



From Close Connections to Feeling Misunderstood: How Parents of Children with Autism Spectrum Disorder Perceive Support from Family Members and Friends

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Abstract

This qualitative study examines the social support of parents of children with ASD living in Québec, Canada. Eighteen parents described their social support experiences before and after their child's first signs of ASD. The results of this study indicate that parents recall many unhelpful support experiences after their child's first signs of ASD. The results also suggest that the parents' support needs greatly outweigh the support they perceive from family and friends. To our knowledge, this study is the first to recognise that receiving adequate social support requires significant involvement from parents who find themselves having to compensate for the lack of knowledge about autism in the general population. The results of this study put forth the active role that parents play in the reshaping of their support relationships and highlight the changes that occur in these relationships over time. Implications for practice and future research are discussed.

Keywords: autism spectrum disorder, social support, families, parenting, coping

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder predominantly characterized by persistent deficits in communication and social skills as well as restricted and repetitive patterns of behaviours, interests or activities (American Psychiatric Association, 2013). Although there are significant differences in the experiences of each family, an ASD diagnosis usually signals the beginning of a long period of adjustment for parents. Indeed, parents of children with disabilities often assume demanding responsibilities that greatly surpass the implications of raising a typical child (Home & Pearce, 2003). In addition to completing usual parenting functions, such as ensuring that their child develops and becomes autonomous, parents of children with ASD must also take into account the particularities of ASD, as well as frequently associated problems such as feeding issues (Zhu & Dalby-Payne, 2019), gastrointestinal problems (Chaidez et al., 2014), sleep disturbances (Glickman, 2010) and other psychiatric disorders, such as depression, anxiety and attention-deficit/hyperactivity disorder (Matson & Cervantes, 2014). Parents, particularly mothers, must also contend with a multitude of additional stressors such as job loss (Cidav et al., 2012), fewer employment opportunities (Maich et al., 2019), financial strain (Nealy et al., 2012) and stigma (Bessette Gorlin et al., 2016).

Mounting evidence suggests that parents of children with ASD experience a significant amount of caregiving burden and stress. For instance, a Canadian meta-analysis reveals that parents of children with ASD experience more parenting stress than parents of children with other disabilities, such as Down syndrome, cerebral palsy and intellectual disability, as well as parents of typically developing children (Hayes & Watson, 2013). Additionally, the results of a study comparing the parenting stress of American versus Chinese parents of children with ASD suggest that these high parenting stress levels are consistent across cultures (Wang, 2016). In this study, 96% of Chinese parents and 81% of U.S. parents had stress levels at or above the 85th percentile on the Parenting Stress Index, one of the most commonly used parenting stress measures (Hayes & Watson, 2013).

Given the stress associated with parenting a child with ASD, many researchers have studied predictors of wellbeing and coping in these parents. One coping strategy repeatedly identified by researchers is the use of social support, often characterized in terms of the perceived availability and help from family members and friends. For example, results stemming from a Canadian study comprising 283 mothers of children with ASD aged between 2 and 5 years old suggest that high levels of social support are associated with lower levels of parenting stress. The results from this study also suggest that mothers with high levels of social support at the time of their child's diagnosis experience less parenting stress two years later (Zaidman-Zait et al., 2017). Unsurprisingly, access to social support has, among other things, been associated to greater levels of daily positive mood (Pottie et al., 2009) while lower levels of social support have been associated to depression and anxiety (Boyd, 2002). Interestingly, social support is believed to impact parents differently depending on the source of support. For instance, correlational data suggests that support from friends is likely to be associated with increased life satisfaction, psychological wellbeing and positive affect whereas support from family is associated with optimism (Ekas et al., 2010). Also, it is important to note that research suggests that *perceived* support is most relevant when studying these parents' wellbeing (Robinson, 2019).

Unfortunately, available research suggests that the social support needs of parents of children with ASD are often unmet (Bromley et al., 2004; Brown et al., 2012; Cappe & Poirier, 2016; Kiami & Goodgold, 2017). This seems to particularly be the case for mothers (Hartley & Schultz, 2015) who are most often the child's primary caregiver. For example, results stemming from a qualitative study of 15 families of children with ASD from Québec suggest that parents of children with ASD often deem the support they receive from family and friends as inadequate or insufficient. In more severe cases, parents in this study even described the support they received as harmful (des Rivières-Pigeon et al., 2015). In another study carried out on 112 mothers of children with ASD from Québec, less than half of the mothers reported feeling as though instrumental support, such as babysitting or domestic care, was available from family and friends. Alarming, the absence of this type of support was strongly associated to psychological distress (Courcy & des Rivières-Pigeon, 2013).

Research suggests that parents of children with ASD often feel stigmatised and misunderstood (Bessette Gorlin et al., 2016). Unsurprisingly, this is believed to impede their ability to connect with and receive support from family members and friends (Altiere & von Kluge, 2009; Galpin et al., 2018; Safe et al., 2012; Stoner & Stoner, 2016). Results stemming from a qualitative study exploring the impact of autism on parents, particularly on the careers or primary caregivers, reveals that these parents often lose meaningful work relationships at a time when such relationships could be a source of support. The parents in this study also reported feeling as though their family members were reluctant to engage with their child, which left them feeling very isolated (Stoner & Stoner, 2016). Parents of children with ASD therefore seem to experience loss of support at a time when they may need it the most.

A study conducted on 500 parents of young children with ASD from multiple countries, including Canada, the United States and Australia, reveals that other parents of children with disabilities, particularly other parents of children with ASD, are the most frequent source of information and support for parents of children with ASD (Mackintosh et al., 2005). Similarly, the results of a qualitative study suggest that mothers of children with ASD often turn to other mothers in similar situations due to feeling misunderstood by others (Safe et al., 2012). That said, the results of this same study also reveal that relying on other parents for support made some mothers feel as though their life was centered around ASD, which left them yearning for friendships with parents of typically developing children (Safe et al., 2012). Taken together, these studies highlight that developing and maintaining meaningful friendships while parenting a child with ASD can be quite challenging.

It is our perception that the research on the social support experiences of parents of children with ASD is currently incomplete and contradictory. For instance, social support is repeatedly cited as a useful coping strategy for parents, yet studies indicate that parents often perceive such support as unsatisfactory. Additionally, whilst parents of children with disabilities, particularly other parents of children with ASD, are often cited as a newfound source of support for parents in the literature, it remains unclear if this support is, in fact, satisfactory. Also, at the present time, most available research is derived from cross-sectional data, which does not allow for an in-depth understanding of the changes occurring in the parents' support relationships over time. That said, akin to parents of typically developing children, parents of children with ASD likely experience different stressors and support needs at different times in their lives. Alas, these evolving needs

are not reflected in the current literature. Indeed, most available research on this topic only allows for a snapshot of the social support experiences of parents.

Despite being the most common and fastest growing developmental disorder in Canada (Canadian ASD Alliance, 2019) and affecting 1 in 64 children and their families in the province of Quebec ((Public Health Agency of Canada, 2018), very little is known about the social support experiences of parents of children with ASD in this province. An in-depth investigation of the social support experiences of parents of children with ASD from Quebec, including the changes that may occur in their support relationships over time, is strongly warranted.

Objectives

This study aims to document the social support experiences of parents of children with ASD living in Québec, Canada. This study also aims to describe how this support changes over time.

Method

The results presented in this article stem from a larger research project aiming to understand the social networks and financial situation of families of children with ASD from Québec, Canada. This project was approved by the *Université du Québec à Montréal* ethics board. Participants were recruited in 2015 through a call for participation published on three Facebook groups including parents of children with ASD. In order to participate, parents had to live in the province of Quebec (Canada) and have a child between the ages of 4 and 10 who had been diagnosed with ASD in the last four years. Thirteen families residing in various regions of Québec (Canada) participated in the study.

The sample included parents from varying socio-economic levels, educational backgrounds, as well as family and marital situations. Two participants (one mother and one father) were single parents and two families in this sample were blended families (one or both parents had children from previous relationships). In four of the families, including one blended family, both parents agreed to participate in the study. The remaining participants singly participated in the study. Two of the mothers in the sample worked full-time, six worked part-time, three were not employed at the time of the interview, and one was on maternity leave. All fathers were employed full-time at the time of the interview, with the exception of one participant who received unemployment benefits. Ten families in the sample had more than one child and two families comprised more than one child with a developmental disorder. A total of 18 individual semi-structured interviews were conducted with 11 mothers, one mother-in-law and 6 fathers. Each interview lasted between 90 minutes and 150 minutes. Most of the interviews took place at the participants' homes but some took place elsewhere, such as at the participant's workplace or in a library. One interview was conducted via Skype due to the geographical distance between the interviewer and the participant. See Appendix A for participant demographics.

All participants first answered questions regarding their employment and family situation.

They were then asked about various support relationships at significant moments in their child's life, such as the child's diagnosis. These questions were the main focus of the interview. Finally, the participants also provided information about their financial resources. The families' finances will not be discussed in this article. See Appendix B for sample interview questions.

An undergraduate student transcribed the content obtained during the interviews. A dual deductive/inductive approach was then employed to allow for an in-depth analysis of the data. First, an inductive analysis of the data was conducted to understand the evolution of the family and friend relationships of each participant at different periods in the child's life (ex. before the child's first signs of ASD, at the time of the diagnosis, a year after the child's diagnosis). The obtained data was then analysed through the lens of the social exchange theory (SET), as described by Smith, Hamon, Ingoldsby, and Miller (2009). The SET focuses on the dynamic nature of relationships and strives to explain how relationships are formed, maintained and dissolved. It has been applied to various areas of research and has often been used to understand the decision-making process that takes place in close relationships, such as filial relationships (Smith et al., 2009).

The thematic analysis method (Braun & Clarke, 2006) was used to analyze the data and a qualitative data management software program, N'Vivo10, was used to organize the data. Excerpts and sample questions were translated from French to English for the purpose of this article. To protect the participants' confidentiality, all identifying information was changed.

Results

Overall, the social support parents described varied greatly from one family to the next. This was expected considering the fact that the families in our sample varied in regard to their socioeconomic status, marital status and immediate environment. Nonetheless, certain themes emerged.

Before the Child's First Signs of ASD

Most parents in our sample reported that the support they perceived from family and friends before their child's first difficulties was satisfactory. Interestingly, the type of support parents perceived from family members greatly differed from what they perceived and, most importantly, wanted from friends.

Instrumental Support: A Gendered Source of Support from Family Members

Before the child's first difficulties, most parents in our sample described acquiring instrumental support (i.e., help with household chores, manual labor, financial assistance, and babysitting) from family members. Per our analysis, instrumental support was most often provided by the child's grandmother. A mother describes:

My mother-in-law is the person who helped us the most. [...] She usually babysits one or two weeks during the summer since [our son] started school. [...] She's really helpful. [...] She's like our saviour (M6).

Indeed, instrumental support was most often given by the parent's own mother or mother-in-law. In most cases, this support was welcome, appreciated and seemed "normal and expected". As explained by a mother, "It's what you would expect a parent to do" (M13). Interestingly, our analysis suggests that the parents' fathers (the child's grandfathers) were much less likely to offer such support. This gendered division of support was reflected in most families and the absence of instrumental support from the child's grandfather often seemed to go unnoticed at this point in time.

Parents with siblings often described a similar gendered division of support from their sisters and brothers. For instance, a mother explained that her brother occasionally offered support by helping with manual labour whereas her sister provided ongoing support and was very involved in the child's life:

I have a sister who often spend time with my son. She even lived with us before [his first signs of ASD]. [...] She eats dinner with us, she comes to his soccer games. She is very present as an aunt. [...] I see [my brother] when I need help with physical labour. He helps us in different ways (M10).

Alas, some parents in our sample described having strained relationships with one or more family members before their child's first difficulties, which did not allow for much support:

I talk to my dad once in a while [but] I cut all ties with my mother years ago because she was extremely negative and... I just couldn't do it anymore. If I need my dad, I call him but not my mom (M7).

"Our Friends are not Babysitters"

In addition to the support they obtained from family members, parents described engaging in meaningful friendships before their child's first difficulties. That said, the support parents perceived from friends usually differed from that of family members. Indeed, whereas most family members supported parents by helping with childcare, domestic work and, in some cases, by offering financial support, friends seldom offered this type of support. Moreover, parents described not *wanting* their friends to provide such support. As a father explained: "I wouldn't ask my friends [to babysit]. I would ask my family for that." (P6). Accordingly, many parents in our sample expressed that their friendships fulfilled different needs than their family relationship.

Our friends are not babysitters [...] We wouldn't ask [our friends to help us with our children]. [...] We confide in them. They are very much there for psychological support (M5).

Indeed, many parents in our study reported that they did not wish to receive help with childcare from their friends, preferring to share moments of emotional support (i.e., sharing thoughts or emotions) or recreational support (i.e., moments of leisure) with them instead. Additionally, contrarily to how they described their relationships with family members, most friendships were characterized by mutuality and reciprocity:

[Our friends] are there for moral support. [...] Sometimes I listen to them when they have problems with work or friends or family. It's give-and-take (M6).

When describing the time before their child's first difficulties, many parents in our sample cherished the close connections they had with their friends and fondly remembered friendships they had preserved over several years. In many cases, sharing the same interests and hobbies, seemed to greatly to strengthen these bonds.

I have a friend I have known for over ten years. [...] He is also an intellectual person, so we spent a lot of time talking, working on projects together (F3).

After the Child's First Signs of ASD

A trend emerged from the data after the child's first signs of ASD. Regardless of the support experiences they recalled from friends and family before their child's first difficulties, most parents in our sample perceived the support they received as less satisfactory. In many cases, this moment seemed to mark a turning point.

Support Needs that Greatly Outweigh Available Support

Alarmingly, after the child's first difficulties, the parents' support needs greatly outweighed the support they received from friends and family. Also, the support parents did in fact receive was often perceived as less suitable. In other words, support that was once considered adequate and useful, quickly became insufficient due to the parents' rapidly increasing support needs.

For example, due to costly interventions, as well as loss of income, the need for financial support grew considerably for many families. That said, financial support from family members was often perceived as sporadic, insufficient and disconnected from the parents' support needs. In fact, the financial support parents received before versus after their child's difficulties seemed to change very little, despite the parents' growing needs for such support.

[My parents] give us gifts sometimes. But if I ask them for money, their answer is no. [...] So I never ask them for anything. Sometimes, though, they surprise us. [...] If they give me money to buy a car, well it

decreases my monthly bills and so... I can spend more money on the kids (M2).

Although the parents in our sample reported feeling relieved after receiving financial support, they also felt as though it was “not enough”. The inadequacy of financial support embodies the parents’ support experiences in general: support that was once perceived as adequate and appropriate no longer corresponded to the parents’ support needs.

From Close Connections to Feeling Misunderstood

Many parents in our sample described experiencing a shift in their relationships with family members and friends after their child’s first difficulties. Although these changes were rarely openly acknowledged, almost all the parents in our sample described feeling judged and misunderstood by their loved ones at this point in time.

I used to be close with my mom and dad... I still am and they still come visit us every other weekend, but things changed. [...] They never said it out loud but... it’s not easy [for them] to come to our house. I think it tires them (M1).

The support [our parents gave us] was as frequent [after the diagnosis] ... But it was different... There were more negative comments. They told us we needed to discipline our child more (M2).

I have a few girlfriends that I see a lot less than before. I just don’t feel like it anymore. I feel judged ... I feel like I just can’t talk about [my difficulties] (M13).

Indeed, many parents in our sample described their relationships with friends and family members as “different” after their child’s first signs of ASD. In many cases, parents remembered feeling disappointed as they realized that their loved ones seemed to know very little about autism.

I had to set boundaries with my brother. One time, at a family reunion, I had to say, ‘That’s enough!’ He kept asking ‘What’s wrong with your kid? Why is he like that?’ ‘Well, we told you he has autism!’ (M13)

Expectedly, lack of awareness and understanding, particularly regarding the day-to-day life and workload associated to parenting a child with ASD, often left parents feeling judged and misunderstood and hindered their ability to connect with and receive support from their loved ones.

A Price to Pay for Support

Many parents in our sample explained that maintaining support relationships in which they felt misunderstood or judged required a lot of “work” as they constantly found themselves having to explain autism or their child’s behaviour to others:

It really surprised me because I assumed that because she was my best friend, she would learn about autism but when we told her the diagnosis she said: “Yeah, but he doesn’t look like the *retards* we knew when we were younger!” I was shocked. It made me feel weird and I realized that I really had to educate those around me (M12).

Unlike parents of typical children, the parents in our sample found themselves regularly having to clarify their support needs to the child’s grandparents who did not adapt to the child’s needs, instead treating him or her like a typically developing child. Doing so significantly increased the parents’ workload, especially when the grandparents did not collaborate:

[When their grandparents] babysat them for the first time, I gave them very simple instructions to follow. Well, the rules weren’t followed so I was stuck with two constipated kids so... it was tough (M7).

[My mom] says that she gets it but... she doesn’t. She tried babysitting my son twice and the second time, I had enough. It’s not that she has bad intentions; she just doesn’t follow my instructions. My son had finally learned new skills at daycare, but after spending time with her, he regressed. I had to start all over (F3).

Our analysis in fact revealed that there was quite often a “price to pay” for social support. Not only did parents have to invest time and energy in explaining autism and the specific needs of their child to others, they also found themselves having to compensate for others’ shortcomings and inadequacies when they did, in fact, receive support. Additionally, in some cases, regardless of the parent’s efforts, the support they received simply did not correspond to their needs:

My wife’s parents were in denial [at the time of the diagnosis]. [...] They weren’t receptive, they weren’t helpful. [...] They have never been emotionally supportive people, but they really helped us financially. They were very generous. They gave us clothes, appliances. [...] It was their way to support us (F2).

Taken together, these examples illustrate that the mere presence of support was, in many cases, not enough. Instead, parents voiced a desire for support that was congruent with their growing and varied support needs. That said, such support required an understanding of the child’s difficulties, as well as the day-to-day implications of parenting a child with ASD, thus involving “work” on the part of the parent who often found him or herself compensating for the other’s lack of skill and knowledge.

Unsurprisingly, for parents who already had strained relationships with family members, this period was particularly challenging:

The period surrounding the diagnosis was really hard for me. I was really alone. I didn't have in-laws anymore, I didn't have a partner, my family lived far away... you could say that I didn't have any family left (M11).

It is important to note, however, that although most parents in our sample reported having negative experiences following their child's first difficulties, a minority of parents indicated that this period led to positive support experiences. This support often came from unexpected sources, such as community members:

Often, when our son goes outside, the neighbours will say hi or go on a bike ride with him ... They babysit the children sometimes. [...] Recently, we had an emergency with our eldest and our neighbors babysat our other three children ... So, they are ready to help out (M2).

My wife put an ad in the newspaper looking for a babysitter for children with special needs... And a 16-year-old girl came over and babysat for free [...] She didn't have any professional experience; she just had a big heart. [...] She made a big difference (F7).

Distancing and Cutting Ties with Friends who "Don't Understand"

Following their child's first signs of ASD, the lives of most of the parents in our sample changed drastically. Many mothers left their job or reduced their work hours in order to take care of their child, which had a huge impact on the parents' financial resources and limited the recreational activities they could participate in. Similarly, the behaviours associated with their child's ASD led many parents in our sample to change how and where they spent their time, most of their activities now revolving around their child. Many of the parents thus reported leading profoundly different lives before and after their child's first difficulties, which often left them feeling disconnected from their friends:

I have friends who don't have children. They listen but sometimes I feel like they don't understand. When we told them about the diagnosis, they said "well it could be worst!" [...] you know that they aren't trying to be mean it's just that... they don't understand (M12).

We talk to [our friends] about it but when you don't have the problem, you aren't living it, sure you can listen, but nothing more. [...] They don't understand that just going to a grocery store is hell for us. [...] They don't get it; they don't have that problem (F1).

In addition to feeling misunderstood, many parents in our sample reported feeling judged by their friends, which led them to limit the time they spent with these individuals. In such circumstances, parents reported consciously distancing themselves from individuals who did not contribute positively to their lives or, in some cases, caused harm.

You don't expect having to hide or censor yourself from your best friend... but I had the impression that from the moment I started having difficulties, I was less interesting. My life was too messed up for her! (M7)

We have the impression that we are not understood. [...] [My friends] have neurotypical children who have tantrums once in a while. If I leave home, there are *a lot* of tantrums. We don't go out. We invite people over from time to time, but ... We end up feeling judged, so we space out visits (M1).

Moreover, some parents in our sample described choosing to cut ties from certain relationships as maintaining them required "too much energy":

I choose my friends based on the energy they require. At one point, I had to create a bubble around me and say "OK, there is too much negativity here, this takes too much energy (F7).

The ideal solution for me was to isolate myself. That way I'm sure [my kid] won't bother anyone. Sometimes you go see your friends and you just don't feel like intervening all the time! So, at some point, you tell yourself... It's just not worth it. If I go out, I'll spend more time watching my son and explaining his behaviours ... I won't even appreciate being with my friends (F3).

Indeed, our analysis suggests that the parents' friendships were at great "risk" of dissolution during this period.

Family Relationships: The Exception to the Rule

Many parents in our sample described their family relationships as burdensome. Specifically, they recalled multiple unhelpful and even harmful support experiences with family members, particularly the children's grandparents. In this context, parents often described feeling misunderstood and frustrated with their family members:

[My parents] don't really get it. When my son has a tantrum... they often tell us we could act differently [...] but they don't interfere. So, they

aren't harming us, but they aren't helping us either. They won't support us by saying, "oh my god, I understand" ... no. They don't understand (M1).

[My parents] try to help us. Like, they babysat our boys for two weeks. But when we came to pick up the kids, the first thing my dad said was that they were not well behaved. He screams at my kids, he's always impatient and ... he's really unpleasant. My mom tries to get it, but she is still in denial. For example, when I told her that my dad yelled at my kids, she was insulted that I had criticized my father. She told me: "You do not want us to help you! (M6)

Surprisingly, despite receiving unhelpful and inadequate support, most parents in our sample chose to continue to receive support from family members, which starkly contrasted their decision to end certain friendships. That said, doing so often came at a price. For instance, in order to compensate for their relative's shortcoming, parents reported spending a significant amount of time and energy explaining autism and their child's difficulties. Some parents even enrolled their family members in formal trainings and provided informational material:

Last year, we had to talk to my parents because we were tired of constantly fighting to get them to understand. I think the talk we had with them helped because they are a little more open and involved now. They learn about ASD, they read stuff... (F8).

Everyone has to learn how to interact with a child with special needs. It's new for everyone. We coached my brother-in-law and even sent my sister-in-law to a training. We wanted her to be able to offer psychological support to my wife. My wife asked her to do it (F7).

I always have to explain ... One time, I printed out a letter that explained what autism is. I gave it to everyone in my family (M4).

Interestingly, these results highlight a previously unknown task related to parenting a child with ASD: having to educate others and compensate for their lack of awareness and knowledge in order to receive appropriate support. This task likely exceeds what most parents of typically developing children have to do in order to receive support from family members and friends. This new information also suggests that the mere presence of support (or the number of support sources) cannot speak to how parents perceive the support they receive, nor what receiving such support involves on their part, and highlights the limitations of previous studies on this topic. Per our analysis, a lack of knowledge surrounding autism in the general population seems to be at the core

of many of the difficulties mentioned by the parents in our sample and most likely explains why parents turn to others in a similar situation when in need of help.

Other Parents of Children with ASD: A Cherished New Source of Support

In order to compensate for inadequate or unhelpful support experiences, most parents reported seeking out individuals who better understood them. As a mother explained: “You can’t choose your family or your colleagues... but you can choose your friends.” (M6) Consequently, many parents in our sample reported developing relationships with others who “understood”, particularly other parents of children with ASD:

I tried to explain what autism is to my friends, but ... it’s like if you have cancer. You can explain it to others and the world knows that yes, you need chemo and chemo hurts. But that’s just the tip of the iceberg. It’s just something that you can’t really understand until you have experienced it. So, you end up surrounding yourself with people who understand (F3).

The most helpful and gratifying relationships are with the other moms, the families... Sometimes, we go to McDonalds with our kids when there is no one else there. We call it a McDonald take over! (M7)

Many parents in our sample cherished the special connections they developed with other parents of children with ASD. Contrarily to their relationships with family and friends, the parents indicated that these new support relationships did not require a lot of work. Instead, they were often characterized by flexibility, understanding and non-judgement:

Once a month, I have dinner with other moms. There is no exchange of services. Other times, we go to the park. All us have kids with autism so we don’t feel judged. We know that if we are tired of being there, we can leave. If we feel that it’s not a good day for our kids, we can just leave (M1).

I have a few coworkers that I see outside of work. The four of us have children, and three of us have children with special needs, so we understand each other. One of them is such a good listener and she doesn’t judge. She is amazing (M11).

Still Not Enough

Despite connecting with other parents of children with ASD, many parents explained that their support needs remained unmet: “We went looking for new relationships but... It’s not a very supportive network. You know, when things go wrong, aside from going to Facebook to tell other

parents...” (M1). Understandably, many parents described requiring additional instrumental support and craving rewarding friendships. Developing and maintaining healthy support relationships was important for all of the parents we interviewed. Sadly, our analysis suggests that, despite turning to other parents of children with disabilities, many of the parents’ support needs remained unmet.

Discussion

Human beings are naturally driven toward connecting with others and sustaining belongingness (Baumeister & Leary, 1995). Furthermore, the scientific literature clearly states that the ability to connect with and receive help and support from others, what is more commonly known as social support, is essential for maintaining physical and psychological health (Ozbay et al., 2007). Sadly, the results of this study suggest that many parents of children with ASD from Quebec lack such connection and support.

An important takeaway from this study is that maintaining relationships with friends and family members often involves a substantial amount work for parents of children with ASD. Indeed, the parents in our sample often described having to compensate for others’ lack of awareness and knowledge about autism, which most likely increases their parental stress. To our knowledge, the “work” required from parents who wish to receive support from family and friends had yet to clearly be documented in the literature.

This study is among the first to reveal the active role that parents play in the reshaping of their support relationships as well as the process behind parents’ decision to put an end to unsupportive relationships. The choice to end a support relationship is particularly interesting when analysed through the lens of the social exchange theory, which posits that expectations, as well as cost and benefit ratios, are implicitly used when making choices in social relationships (Smith & al., 2009). Naturally, parents who feel misunderstood or judged by their loved ones most likely anticipate that they won’t receive adequate support from these individuals in the future, which leads them to “cut their losses”.

It is interesting to note, however, that while the social exchange theory seems to explain why parents of children with ASD terminate unsupportive friendships, it does not account for the fact that parents often remain in relationships with unhelpful family members, even when these relationships do not provide them with rewards or, in more severe cases, seem to be quite damaging. A likely explanation for this phenomenon is the fact that family relationships encompass different social rules and expectations than friendships. For instance, exiting a friendship is usually considered much easier than exiting a family relationship. Indeed, you may tell someone “you are not my friend anymore” but cannot state “you are not my sister/brother/parent” anymore (Godbout, 1992). Additionally, the parents in our sample often described their friendships as “give and take”, especially before their child’s first difficulties. That said, they did not describe their family relationships as such. It is therefore possible that parents continue to expect support from family members without an associated cost. Alas, our results suggest that there are, in fact, significant costs associated with receiving adequate support from family members.

Implications for Practice

The results put forth in this study are important to keep in mind when thinking of strategies to help families of children with ASD, as “more support” is not always “better”, particularly if the support is not perceived as adequate by the parents. Rather, the results derived from this study stress the importance of inquiring about the unique support needs of families before intervening. Knowledge about autism, a proper understanding of the family and the child’s needs, as well as sensitivity to the family’s new and transforming reality, are key elements to offer appropriate support to parents. In order to properly support parents of children with autism, family members and friends must therefore adapt to their complex needs and family reality. In fact, providing appropriate support to families of children with ASD often requires the development of “expertise” (des Rivières-Pigeon et al., 2015), which can be acquired by spending a lot of time with the family and the child and, in some cases, by formal training.

The results presented in this study are particularly relevant because they raise the possibility that researchers and health care professionals may not correctly perceive the isolation and lack of support experienced by parents of children with ASD as many of them remain surrounded by family and friends and that the behaviours of others towards them often do not present marked changes. That said, the results of this study illustrate that these parents commonly receive support that they deem as “unhelpful” and that, in many cases, receiving appropriate support significantly increases their workload. Overall, parents of children with ASD seem to find themselves in a particular situation that is not well known nor properly assessed. It is crucial that health care practitioners become more aware of this situation, as it will allow them to accurately assess the needs of each family and, hopefully, properly inform and educate the family’s loved ones.

Limitations

Aside from the typical limitations regarding the generalizability of qualitative studies, a few considerations must be noted. First, our study focused on the parents’ perception of the support they received from their family and friends and did not investigate this support from the perspective of family members and friends. Since support recipients and support providers may have different perspectives about support exchanges (Shumaker & Brownell, 1984), future studies should also investigate the perspectives of the support providers. Also, our sample consisted of parents of 4 to 10-year-old children with ASD. These results may therefore not be generalizable to parents whose children are in a different developmental period. Future studies are strongly recommended to understand the support experiences of parents at different developmental periods, particularly as the child grows older (ex. adolescence, adulthood). Moreover, our sample included both mothers and fathers of children with ASD. That said, research suggests that fathers and mothers have different support needs (Hartley & Schultz, 2015). Future studies should therefore consider examining the support experiences of mothers and fathers separately. Also, previous research has suggested that lower-income parents are at a disadvantage in terms of the support and information they receive. Particularly, lower income families are believed to be less likely to receive support from friends and neighbours, as well as from other parents of ASD (Mackintosh

et al., 2005). Future research should thus consider the socioeconomic status of parents when examining the support they perceive from family and friends. Finally, our results were drawn from a sample of parents living in the area surrounding the city of Montreal (Quebec, Canada). The support experiences of these parents were likely shaped by this province's particular attitudes toward autism, knowledge about autism, as well as availability of resources. Results may therefore not be generalizable to parents in different provinces or countries.

Conclusion

To our knowledge, this is the first qualitative study to examine parents' perception of their support relationships before and after their child's first difficulties. Ours is also the first to highlight the dynamic nature of these support relationships, as well as the decision process behind parents' choice of maintaining, or not, certain relationships. Future research should deepen the understanding of the support these families receive while acknowledging the various relational dynamics at play. An investigation of the support relationships of these parents during adolescence and adulthood is especially relevant as the support needs of parents with children with ASD inevitably change and evolve over time, particularly in times of transition (Meadan et al., 2010).

By sharing these results, we hope that family members and friends, as well as professionals who work with children with ASD and their parents, rethink the way they intervene and offer support. It is also our hope that researchers studying families of children with ASD be mindful of the complexity and the various dynamics at play in these relationships.

Appendix A

Table 1. Participant Demographics

Family	Parent (s) who participated in the study	Education and current job status	Marital status	Children
1	Mother (M1)	Collegial degree, unemployed	Married	4 children, 2 with ASD diagnoses
	Father (F1)	Professional degree, full-time job (45h per week)		
2	M2	University degree, full-time job	Married	4 children, 1 with ASD diagnosis
	F2	University degree, full-time job (42-45h per week)		
3	F3	Collegial degree, unemployed	Separated, single parent	1 child with ASD diagnosis
4	M4	Collegial degree, part-time job (20-30h per week)	Common law spouses	1 child with ASD diagnosis
5	M5	Professional degree, works 2 part-time jobs (20h per week)	Married	4 children, 1 child with ASD diagnosis
6	M6	University degree, part-time job (28h per week)	Married	4 children, 1 child with ASD diagnosis
	F6	University degree, full-time job (35h per week)		

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7	M7	High school diploma, unemployed	Common-law spouses	2 children, 1 child with ASD diagnosis
	F7	High school diploma, full-time job (40h per week)		
8	M8 (Stepmother)	Collegial degree, unemployed (maternity leave)	Married	2 children, 1 child with ASD diagnosis
	F8	Collegial degree, full- time job (37.5h per week, currently on paternity leave)		
9	M9	University degree, part-time job (varying hours, on call)	Common-law spouses	1 child with ASD diagnosis
10	M10	University degree, part-time job (35h per two weeks, following maternity leave)	Common law spouses	3 children, 1 with ASD diagnosis
11	M11	Collegial degree, full- time job (35h per week)	Separated, joint custody of the child	2 children, 1 with ASD diagnosis
12	M12	Collegial degree, unemployed	Married	2 children, 1 child with ASD
13	M13	University degree, part-time job (28h per week)	Married	2 children, 1 child with ASD diagnosis

Appendix B

Sample interview questions:

- Did you see this person often? For what reasons?
- How would you describe your relationship with this person at this time? Was it a rewarding relationship?
- Is this someone who you felt you could count on in times of need?
- What did this person do for you? What did you do for them? What did you do when you spent time together? Could you give us an example?
- Did this person ever help you with your child? Did they offer support, such as babysitting or financial/material support? Did you ever experience conflict about this?
- Overall, did this your relationship meet your support needs or would you have wanted it to be different? How so?

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