

Experience of Autistic Children and Their Families During the Pandemic: From Distress to Coping Strategies

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Abstract

Background. As the COVID-19 pandemic unfolded during Spring 2020, families experienced multiple upheavals, including lockdown, school closures and ruptures in professional services. We wanted to better understand the experience of autistic children and their families in times of crisis.

Methods. 109 parents of autistic children (2.6–18 years) and 56 autistic children (5.75–18 years) from Quebec (Canada) completed an online survey about needs, barriers and facilitators to coping with the pandemic. Quantitative data were analyzed using ANOVA, chi-squares and open-ended questions with thematic analysis.

Results. Half of the parents and children considered the pandemic to be a stressful time. Parents who expressed concerns about their child's development and difficulty managing their child's behaviors during the pandemic were significantly more likely than other parents to report these concerns before the pandemic, along with the following challenges during the pandemic: social isolation, having to pursue academic goals, feeling powerless over their child's behaviors and no routine during the pandemic (all $p < 0.05$). Maintaining social relationships and implementing appropriate strategies, such as a routine, were identified as facilitators by both parents and children. Among children, 92.9% associated technologies with their well-being, but many parents saw too much access to electronics by their child as a barrier, suggesting a need to better understand and use autistic interests.

Conclusion. Both autistic children and their parents identified social isolation as one of the main difficulties during the pandemic. We also need to consider autistic characteristics and children's interests to implement emergency accommodations and services.

Background

The World Health Organization (WHO) declared COVID-19 a pandemic in March 2020, bringing global challenges around the world. For about three months, the entire province of Quebec, like all other Canadian provinces, was locked down, resulting in complete school and childcare services closure, as well as drastically reducing the possibilities of support, both from professionals and relatives. Adaptations were necessary to deal with this situation for the entire population (1-3), but particularly for children with special needs and their families (4-6). From the start of the pandemic, researchers feared that autistic children and their families would face many challenges, such as dealing on their own with pandemic-related stress (7, 8). These families had to reorganize their daily lives, encountered barriers in accessing healthcare and specialized services, and the children experienced many changes in education (4, 9).

Autism is a neurodevelopmental condition marked by deficits in social communication and interactions and by the presence of restricted and repetitive behaviors, interests and activities (10). Given the heterogeneity of autistic characteristics across children, as well as across developmental stages (11-13), many questions remain on how to organize services to meet the needs and particularities of autistic

children and achieve a better family balance while complying with public health guidelines. As the world struggles to adjust to the ongoing pandemic, it is clear that special consideration must be given to autistic children and to adjusting the services to the specific needs of autistic children and their families.

Several studies used surveys with parents for their input on services that better meet the particularities and needs of autistic children and their families (e.g. 14, 15-20). However, few researchers relied on parental expertise to document the needs of autistic children in terms of intervention services to be implemented in emergency situations. In Tway, Connolly (20), parents who completed the Family Crisis Oriented Personal Evaluation Scales (F-COPEs) indicated that having access to social support, redefining stressful events, and seeking information helped their adaptation. In White, Law (21) study, there was a consensus among parents about the importance of access to information and strategies for responding to the crisis. These studies showed that the perspective of parents can be an important source of information because they are good informants for identifying priorities for assessment and intervention services.

Therefore, the goal of our study was to better understand the needs of autistic children and their families in the context of a pandemic and to make recommendations to guide services. We considered important to also get the perspective of autistic children themselves. To do so, we surveyed parents of autistic children and also asked their children about their own needs and perceptions. More precisely, the objectives of our study were 1) to identify the factors that hinder or facilitate daily functioning during the pandemic; 2) to identify the coping strategies to be implemented to ensure the quality of life of children, as well as family balance; and 3) to recommend practices, support mechanisms, and services to be offered by the community, institutions, and government at a time when further waves of pandemic were predicted.

Method

Research Design

Using a mixed research design, the combination of both qualitative and quantitative data helped provide a better understanding of the reality of autistic children and their parents facing the COVID-19 pandemic. To collect the data, we created a questionnaire to be completed through *LimeSurvey*. To obtain a variety of respondent profiles, we also offered the option to complete the questionnaire by interview. The survey took place between July and October 2020. The participants provided informed consent through the online platform or by email. This study was approved by the research ethics committee of XXX.

Participants

Participants were recruited through advertisements disseminated by professional and parents associations and on social networks. Two groups of participants completed the new French-language *Questionnaire on the Needs of Autistic Children and Adolescents During the Pandemic*. One hundred and nine parents of autistic children (88 boys, 19 girls and 2 non-binary) aged between 2.6 and 18.10 years

(15.6% aged between 2 to 6, 50.5% aged between 7 to 12 and 34% aged between 13 to 18) completed the questionnaire (3 parents by phone interview and 106 online) and 56 children (46 boys, 9 girls and 1 non-binary) aged 5.75 to 18 years filled out a sub-section of the same questionnaire. All the participants lived in Quebec, Canada. Inclusion criteria were (1) autism diagnosis for the child, (2) sufficient knowledge of French to answer the questionnaire, (3) child aged 24 months to 18 years old (See Table 1 in Additional file 1 for the socio-demographic characteristics).

Questionnaire

The survey was about the pandemic, more specifically the period of confinement and physical distancing in Spring 2020. It was developed and revised iteratively by the research team, which included clinicians and researchers. It comprised multiple-choice and open-ended questions about sociodemographic and clinical characteristics, pre-pandemic situation, pandemic situation, obstacles, facilitating factors, access to information and services during the pandemic period, perception of the situation during the pandemic period, accommodations, and adaptive strategies. The child section concerned stress and difficulties caused by the pandemic, strategies for facing the pandemic and making it less stressful, and activities to help cope with the pandemic.

Analyzes

The final raw data were imported from LimeSurvey and analyzed with SPSS 25 software. Descriptive statistics were used to provide a general picture of the participants' experiences (stress experienced by parents, facilitating factors, barriers, perceptions of children, access to information and services). One-way analyses of variance (ANOVA) were performed to verify the impact of having difficulties managing child's behaviors during the pandemic (never/rarely vs. often/always) on the level of pandemic-related stress experienced by the parent, as well as on their child's level of stress. Similar ANOVA were performed to assess the impact of having concerns relative to their child's development and behaviors during the pandemic (never/rarely vs. often/always). Additionally, chi-square tests were used to determine if any facilitating factors or barriers impacted positively or negatively the adaptation during the pandemic. Also, thematic analyzes of the open-ended questions on facilitating factors, barriers and parents' recommendations were carried out. One research assistant and one author (XX) independently evaluated the answers and pooled them into categories. Inter-rater agreement was achieved for 20 % of the thematic analysis. Mean inter-rater agreement was 87%. In cases of discrepant category attribution, consensus was reached through discussion with two of the authors (XX and XX).

Results

The results were grouped into six sections: 1) Stress experienced during the pandemic, 2) Factors influencing adaptation during the pandemic, 3) Facilitating factors, 4) Barriers, 5) Perceptions of children, 6) Parents' recommendations.

Stress experienced by parents during pandemic

Almost half of our respondents (45,9%) considered themselves anxious by nature, while only 16,5% reported going through stressful situations quite easily. Also, 52.3% of parents reported having several strategies to cope with difficult situations.

During the pandemic, half of the parents (50.4%) considered it a highly stressful time for them. When asked about the whole family, 41.2% of parents identified the presence of high pandemic-related stress in their family. According to 50.5% of parents, the pandemic became less stressful over time, while 13.8% of parents indicated that the pandemic situation became more stressful.

Parents who reported that their child's behaviors were difficult to deal with during the pandemic reported that the pandemic was a significantly greater source of stress for them, as well as for their child, than parents who did not report difficulties to manage their child's behaviors, $F(1, 107)$ respectively 4.861 and 6.72, $p < 0.05$. Similarly, parents who were concerned about their child's behaviors during the pandemic reported experiencing more stress during the pandemic than parents who were not concerned about their child's development and behaviors, $F(1, 107) = 4.453$, $p < 0.05$.

Factors significantly influencing children's behaviors during the pandemic

Parents who reported that their child's behaviors were difficult to deal with during the pandemic had also reported more difficulty than other parents to manage their child's behaviors before the pandemic ($c^2(1)=26.188$, $p < 0.001$) and were more concerned about their child's behaviors before the pandemic ($c^2(1)= 6,028$ $p < 0.05$). Similarly, parents who reported being concerned about their child's behaviors during the pandemic also reported more difficulty than other parents to manage their child's behaviors before the pandemic, ($c^2(1)=9.159$, $p < 0.05$) and were more concerned by their child's behaviors before the pandemic ($c^2(1)=21.609$, $p < 0.001$). See figures 1 and 2 in additional file 2 for the differences in difficulties to manage child's behaviors and parents' concerns about their child development before and during the pandemic.

However, the characteristics of the child (age, regular vs. specialized class), the parents (salary and educational level), and the family (number of brothers and sisters, presence of a diagnosis in siblings) did not have a significant impact on being concerned about child's behaviors and/or behavior management during the pandemic ($p > 0.1$). See table 1 in additional file 1 for descriptive data.

Some barriers reported by parents had an impact on concerns about their child's development or the ability to manage their child's behaviors during the pandemic. Five barriers were significantly more reported among parents who were concerned about their child's behaviors: social isolation ($c^2(1)= 18.888$, $p < 0.001$), having to pursue academic goals during the confinement, ($c^2(1)=8.155$, $p < 0.01$), working in essential services ($c^2(1)=10.779$, $p < 0.05$), feeling powerless with regards to their child's behaviors ($c^2(1)=16.246 < 0.001$) and their child not having a routine anymore ($c^2(1)=8.970$, $p < 0.005$). Similar barriers were significantly more reported among parents who found their child's behaviors more difficult to manage during the pandemic: socially isolation ($p < 0.001$), having to pursue academic goals,

($\chi^2(1)=8.814$, $p \leq 0.01$), working in essential services ($\chi^2(1)=6.359$, ($p < 0.05$) and feeling powerless with regards to their child's behaviors ($\chi^2(1)=11.155$, $p < 0.001$).

What were the facilitating factors?

Out of a list of 30 individual, family, and environmental facilitating factors, the parents reported which were the most helpful in facing the pandemic. The four most endorsed factors were: *understanding of their child's needs* (73.4%), *establishment of a routine with their child* (66.9%), *good communication between parents* (62.4%), and *possibility of spending time together* (61.5%). See Table 2 in additional file 1 for all the facilitating factors.

In the open question about facilitating factors, parents made 55 statements. Three major themes were extracted through the thematic analysis: 1) use of adapted interventions ($n = 38$, 69.1%), 2) COVID-19 management ($n = 7$, 12.7%) and 3) having access to informal and formal support ($n = 4$, 7.3%).

Parents identified the need to use adapted interventions to respond to their child's specific needs. In this regard, many parents reported the importance of **setting a routine** ("Making sure to have a daily experience anchored in a routine similar to before the pandemic." – Mother of a 12-year-old autistic boy). They also highlighted that they **used materials suitable to autistic characteristics** ("A heavy blanket...really helped to calm the anxiety. He always has it with him." – Mother of an autistic boy aged 6 years and 11 months). Parents mentioned that they **respected the needs** and the limitations of their child ("I spoke with him to know what he needed." – Mother of an autistic boy aged 13 years and 4 months).

The parents managed the COVID situation with their child. To do this, they gave their child **information and answered their questions** ("Talking with him, without hiding reality too much and reassuring him." – Mother of an autistic boy aged 13 years and 1 month). They also **downplayed the situation** ("Having an attitude of downplaying events. Without denying the impact of COVID, not talking about it constantly and thinking about it all the time." – Mother of a 12-year-old autistic boy).

Informal support (conjugal, parent, and children) and formal support (specialized services) were helpful for the families. Parents highlighted the importance of having access to **specialized services** for their children but also for themselves ("Having the chance to consult my psychologist to vent and help me continue." – Mother of two autistic boys, one aged 9 years and 3 months, one aged 7 years and 6 months).

What were the barriers?

Out of a list of 17 barriers, parents reported which were the most difficult to face during the pandemic and hindered their child's adaptation. The three main barriers were: their child having too much access to electronic devices (56%), being isolated from their relatives (55.1%), and having to pursue academic goals (while schools are closed) (51.4%). See Table 3 in additional file 1 for all the barriers.

In the open question on barriers to their child's adaptation during the pandemic, parents made 52 statements. Four major themes were extracted through the thematic analysis: 1) closure of specialized resources (n=11, 21.2%), 2) lack of opportunities for social interactions (n=9; 17.3%), 3) inappropriate school support (n = 6, 11.5%), and 4) challenging behaviors (n=5; 9.6%).

The closure of specialized resources was perceived as very difficult, with sometimes dramatic consequences. Autistic children and their parents felt isolated given the **lack of access to specialized services** ("We were left completely alone and without resources, services, or respite. My child completely decompensated and we couldn't even help him, and nobody could help us either." – Mother of an autistic boy aged 8 years and 10 months). Some children went through a period of **regression** ("The children regressed in their already-limited social skills." – Mother of a 12-year-old autistic boy).

Parents also identified a significant impact of the pandemic on their child's social interactions. Hence, they reported a **lack of social interaction** opportunities for their child ("The thing that is hardest for my child is that he can't have friends over for his birthday because they don't understand doing social distancing." – Mother of an autistic boy aged 9 years and 11 months). Parents also found their child to be **lonely** ("My child was more withdrawn and a little less communicative." – Father of an autistic boy aged 11 years and 9 months).

The support, services and teaching opportunities offered by schools varied greatly (during the pandemic). Some parents reported that **school support was not adapted** to the particularities of autistic children ("Students integrated in regular classes who were not failing were not targeted for individualized support [vulnerable is not only when it shows in the academic statistics and scores]." – Mother of a 15-year-old autistic boy).

Also, many challenging behaviors were reported, particularly those related to **anxiety** ("It was hell. Tantrums, generalized anxiety: fear of dying, of choking, of breaking a bone, etc." – Mother of an autistic boy aged 7 years and 4 months) and to **opposition** ("A lot of violence with his little brother." – Mother of an autistic boy aged 7 years and 4 months).

Perceptions of children

While 38.5% of parents identified the presence of elevated stress in their children, 50% of the children pointed out that the pandemic was stressful for them. In terms of facilitating factors, 92.9 % of children indicated that **electronics** were what made them feel good during the pandemic. In an open-ended question about what helped reduce their stress, more than a quarter of the responses were about electronics ("lots of Minecraft and YouTube" – 11 years and 10 months autistic boy, "listen to YouTube videos" – 12 years and 10 months autistic girl, "play videogames" – 11 years and 9 months autistic boy, "play with my computer at Hello Neighbor and Nintendo switch at Mario Maker" – 13 years and 2 months autistic boy). The two other most important factors, **board games** and **reading**, were identified by 37.5% and 35.7% of children, respectively. When children were asked in an open-ended question what they would recommend to a stressed friend during the pandemic, 29% of all the recommendations were

related to the social sphere, the main theme of this qualitative analysis. In 70% of cases, these recommendations pertained to communication, and closeness with their parents (“To talk to his mother to get help” – 18 years old autistic boy, “Talking to his parents” – 12 years autistic boy), whereas the rest concerned visiting family and talking to trusted adults (“If he has a trusted adult, tell him he is stressed” – 15 years and 5 months autistic boy, “Go see the family” – 7 years and 2 months autistic boy).

As highlighted by the parents, the lack of socialization (namely “not seeing my friends” – 14 years old, autistic boy) was identified as an important barrier by 57.1% of children among a list of 7 potential barriers. Next came the fear of catching the virus (48.2% of the children) and the change in routines (35.7% of the children). The quarter of all the answers to the open-ended question about what they found difficult during the pandemic were also about the limitation of social interactions (“not see my family and friend” – 14 years old, autistic boy, “not being able to spend time with my grand-parents” – 16 years and 2 months, autistic boy, “having to go to high school and not being able to see my school, my friend and my teachers [from elementary school] one last time” – 12 years, autistic boy).

Parents’ recommendations for service organizations and government to increase support to autistic children and their parents during the pandemic Parents were asked what they would recommend for public services in the context of the pandemic. Parents made statements about what could be improved in specialized services (n = 33) and respite (n=14), in schools (n = 31) and by the government (n = 4). In this section, they again stressed the lack of socialization (n=21) as an important factor to consider. *Specialized Services*

There was a consensus among the parents regarding the importance of having **access to services** for all autistic children (“At the very least, we would have liked the services that support the families who have a child with ASD to be considered essential services.” – Mother of an autistic boy aged 6 years and 11 months). The importance of **access to experts in autism** was also stressed by many parents (“Access to psychoeducators.” – Mother of a 13-year-old autistic boy; “Easy consultation with a physician or psychologist specialized in autism.” – Mother of a 13-year-old autistic boy). Access to specialized services during the confinement varied among children. Parents indicated that it should be a priority to maintain basic services in **various forms**, such as online interventions or phone support (“It would have been relevant to continue the support even remotely, because we no longer had any services, e.g., the educator was calling once a week, but we would have liked the special education technician to be more present.” – Mother of an autistic boy aged 6 years and 11 months). However, considering the heterogeneous profiles of autistic children, these services were not always suitable for meeting their variable needs. Sometimes, **direct interventions** were necessary but unavailable (“I would have needed more in-person visits from the caseworkers, notably from the intervention center, rather than just talking on the phone for two to three months. I was really all alone.” – Mother of an autistic boy aged 7 years and 4 months). Finally, the importance of having **access to respite** was stressed repeatedly by parents (“There has to be respite for the families and targeted interventions by qualified personnel to help the families. At the time, there was literally nothing and we were left to ourselves without support of any kind.” – Mother of an autistic boy aged 15 years and 1 month).

School The main theme extracted was the **importance of establishing a routine**, with the help of better monitoring from the teacher and other professionals from the school, as well as the implementation of adapted academic work (“Supply tools to help set up a routine and not just worklists.” – Mother of an autistic girl aged 12 years and 10 months). The second theme was the **importance of follow-up** by the school professionals (“That the caseworkers who already know the child continue their calls.” – Mother of an autistic girl aged 12 years and 10 months). Finally, **access to specialized counselors and maintenance of in-person schooling for children in specialized classes** was the third theme identified by the parents (“Back to school for ASD classes in a regular school.” – Mother of an autistic boy aged 7 years and 1 month). **Government** Parents highlighted the importance of having access to **consistent information**. Some autistic children obtained information directly from the media. Constant changes in the information provided about the pandemic and lockdown had a negative impact on them. The parents of autistic children reported the need for accurate information about the virus, but also about health measures implemented in society, work, schools, and preschools (“Avoiding making government announcements that change quickly like the non-resumption of classes in September and then the total opposite a few days later.” – Mother of an autistic girl aged 13 years and 6 months). Parents also underlined the necessity of **financial compensation**, especially to have access to respite during periods of confinement (“Even the government could have helped by offering money to at least get respite. I was just left on my own and I had parental anxiety and exhaustion.” – Mother of an autistic girl aged 11 years and 6 months).

Discussion

In this study, we documented the experience of autistic children and their families during the pandemic using a survey of parents, who shared their experience and made recommendations on how to improve services in response to the COVID-19 pandemic. We also administered a subsection of the questionnaire to their autistic children, to better understand their specific needs. To our knowledge, only one study has directly surveyed autistic children on their perceptions of the pandemic, but with a small sample (22).

The results of the parent section showed that half of the sample considered the pandemic to be a highly stressful time. Several factors likely contributed to heightened concerns about their child’s development and/or difficulties in managing their child’s behaviors during the pandemic. Some factors were related to the pre-pandemic period: concerns about their child’s development or difficulties managing their child’s behaviors, whereas others were specific to the pandemic: social isolation, pursuit of academic goals, feeling powerless about their child’s behaviors and no routine.

These factors were linked to the three main facilitators that the parents identified in closed and open-ended questions: understanding their autistic child’s characteristics, implementing appropriate interventions, such as setting up a routine, and maintaining social relationships.

In addition, too much access to electronics was identified as one of the main obstacles.

Half of the children also considered the pandemic as a stressful time.

Like their parents, the children identified lack of socialization as a main barrier and stressed the importance of a routine.

However, they held an opposite view to that of their parents regarding access to electronics. Indeed, the children reported how access to electronics and to their activities or objects of interest (e.g., board games, reading) contributed to their well-being.

Finally, the survey also allowed parents to share their suggestions by responding to the following question: What practices or services could have been put in place, in particular by childcare centers, schools, workplaces, healthcare centers, community organizations, and government, to promote your autistic child's adaptation during the pandemic?

First, parents stressed the importance of maintaining access to specialized services for autistic children and that services for autistic children should be considered essential.

These services could take various forms: direct interventions (e.g., access to respite), telehealth interventions, or phone support.

Second, parents pointed out that schools must ensure a regular and targeted follow-up with autistic children and offer specialized services if necessary.

Third, parents underlined that government should provide accurate information about COVID-19 and the measures available for autistic children and their parents.

Finally, parents indicated that all environments must be flexible to the reality of families with autistic children and must take into account autistic characteristics.

What we learned from this research: Support for autistic children and their parents, social interactions, and accommodations for autistic interests

Three elements were consistently highlighted by parents and autistic children in this study: the importance of supporting autistic children and their parents, the need for social interactions, and the place for autistic interests. Beyond the current pandemic, understanding these factors is important to better guide interventions for autistic children.

Supporting autistic children and their parents

Regardless of the parent profile (half of the sample of parents considered this period particularly difficult), a general consensus emerged among the parents on the importance of having access to information to understand their autistic child's characteristics and to put in place measures suited to these characteristics. The pandemic has shown that interventions for autistic children must not only target the children directly, but also provide parents with tools to better understand and support their child in the form of parent-mediated intervention (9, 23, 24). In our study, setting up a routine was a main facilitating factor identified by the parents and a helping factor reported by the children. Previous studies on the pandemic have also highlighted the importance of setting up a routine, organizing free time, and structuring activities (9, 23–25).

However, to better adapt the environment to the particularities of their autistic child, parents need to be supported.

The situation has been more difficult for families with autistic children who were struggling before the pandemic. Our study showed that the pandemic amplified parents' concerns and exacerbated difficult behaviors already present in the children. Similarly, Colizzi, Sironi (26) further observed that autistic children with pre-existing behavior problems were twice as likely to have more frequent and more intense behavior problems than before. These findings also highlight the importance of having ongoing support in the interventions that parents can implement in their children's daily lives, even outside of a national emergency (4, 9). In this regard, services should be increased for autistic children who are already experiencing difficulties. Contrariwise, in many studies, parents said they lost services during the pandemic and that little support was available (e.g. specialized services, classes, respite, medical support; 7, 9, 27). In short, it is imperative to ensure the continuity of autism interventions, propose direct and indirect intervention methods, and adapt the modalities and intensity of interventions to the child's profile.

The need for social interactions

Isolation had many consequences for children in the general population. It is not surprising that caregivers and families of autistic children felt isolated during the pandemic (more than 70% of the sample in Salt (28)).

Parents also stressed the importance of socialization in their autistic children's lives. Our results highlighted a paradoxical aspect of autism: whereas this condition is indissociable from significant social deficits in popular belief, the lack of social contact represented the main obstacle reported by autistic children as well as by their parents during the pandemic.

Although there is an abundant literature on social interactions in autism, the literature concerns more particularly the deficits in social interactions. These deficits dominate the diagnostic criteria of the autism spectrum: "Deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used in social interaction, deficits in developing, maintaining, and understanding relationship" (p. 50; 10).

Given these deficits, many autism intervention programs aim to improve social skills, social cognition, and social interaction with social skills group interventions, with mixed results (for a review, 29, 30). These studies have largely documented the issue of autistic children's deficits in social interactions, but do not provide information on their *need* for social interaction. Like in Altable (23) and Pellicano, Brett (8), our study shows that social interactions are indeed important for autistic children and could offer a new way to approach this issue, beyond the deficits. It would be relevant to consider, maintain and foster social interactions in autistic children's lives, because they seem to play a major role in these children's well-being and quality of life.

Are autistic interests facilitators or obstacles?

The presence of intense interests is a diagnostic criterion in autism. Interests are described as “highly restricted, fixated and abnormal in intensity or focus” (p. 50, 10). The way people understand autistic interests is changing; perceptions of these traits are more positive than they once were (31–35). As reported in the DMS-5, “special interests may be a source of pleasure and motivation and provide avenues for education and employment later in life” (p. 54, 10). Several studies support the view that these interests may be associated with well-being (36–38). Accordingly, almost all children in our study emphasized the importance of electronic tools for their well-being.

Despite half of the parents identified too much access to electronics as a major barrier, two thirds of the parents had implemented broader access to technologies to accommodate their children.

Access to electronics was also the third of 15 items identified by the parents as helping their children to cope.

These results show that parents recognize the importance of interests in their autistic children’s lives. However, parents must be better equipped to know how to use their children’s interests in their daily lives. Also, considering the early interest for technologies (Larose et al. in press), their positive integration in autistic children’s daily lives should be better understood (39).

Recommendations for better organizing services for autistic children in an emergency

Parents made specific recommendations on how to provide services to autistic children during the pandemic. These recommendations can guide the services offered in any emergency. Some guidelines may facilitate their implementation. First, as pointed out by Aishworiya and Kang (4), various services (education and healthcare) and government need to work together to find appropriate ways to meet the needs of autistic children and their families. To this effect, autism experts must be included in the decision making to organize services in an emergency like the current pandemic. Also, government authorities must develop guidelines to support assessment and intervention services for autistic children and to make the information available (4). Second, specialized services must be better trained in virtual assessment and intervention to meet autistic children’s needs in times of emergency. In this regard, access to services can be improved through the use of telehealth platforms (9, 24, 27, 40, 41). Third, specialized services must take into account the needs and well-being of the children, but also of the entire families. It is important to protect the mental health of children, but also of their caregivers (4, 5).

Limitations

Although our sample included children of all ages and allowed the collection of qualitative and quantitative information, the number of participants remained small and the average age was high (mean = 11 years), while the situation could be less difficult for parents of older children as suggested in Colizzi, Sironi (26) study. We did not collect information about the specifiers associated with the autism diagnosis or the presence of co-morbidities and there was no formal verification of the diagnosis. Also, the questionnaire was developed and revised by clinical and research experts, but it has not been validated. However, the questionnaire provided a portray of the experience of autistic children and their

families by directly surveying the parents and the autistic children themselves and providing recommendations for services and governments.

Despite our efforts to reach a diversity of families via associations and by offering different modalities to complete the questionnaire, the sample was not representative of the diversity of socio-ethnic profiles and family structures. Also, it was not representative of the reality of the most vulnerable families, and of parents and children who experienced the most considerable stress during this period. However, one of the main findings of the study concerned the recommendations offered by parents, which can be informative for a large spectrum of families, even those who have fewer resources and who generally face more barriers to accessing healthcare (4, 40).

Conclusion

Our study adds to the collective effort to improve services for autistic children and their families during crises and emergency situations. One of its original contributions was to consider the perspective and recommendations from autistic children themselves, in addition to that of their parents. Contrary to popular beliefs, both autistic children and their parents identified social isolation as one of the main difficulties faced during the pandemic. Our study also highlighted the need to consider autistic characteristics and the interests of the child to implement emergency accommodations and services, while avoiding ruptures in services.

Declarations

Ethics approval and consent to participate

The participants provided informed consent through the online platform or by email. This study was approved by the research ethics committee of XXX (#2021-1227).

Consent for publication

Not applicable.

Availability of data and materials

The datasets during and/or analyzed during the current study available from the corresponding author on reasonable request. The datasets supporting the conclusions of this article are included within the article and its additional files 1 and 2.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

XX, XX, XX contributed to the design of the study. XX, XX, XX, XX collected the data. XX, XX analyzed the data. XX drafted the manuscript. XX, XX, XX, XX reviewed the manuscript. The manuscript has been read and approved by all the authors.

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Tables

Due to technical limitations, table 1, 2, 3 is only available as a download in the Supplemental Files section.

Figures

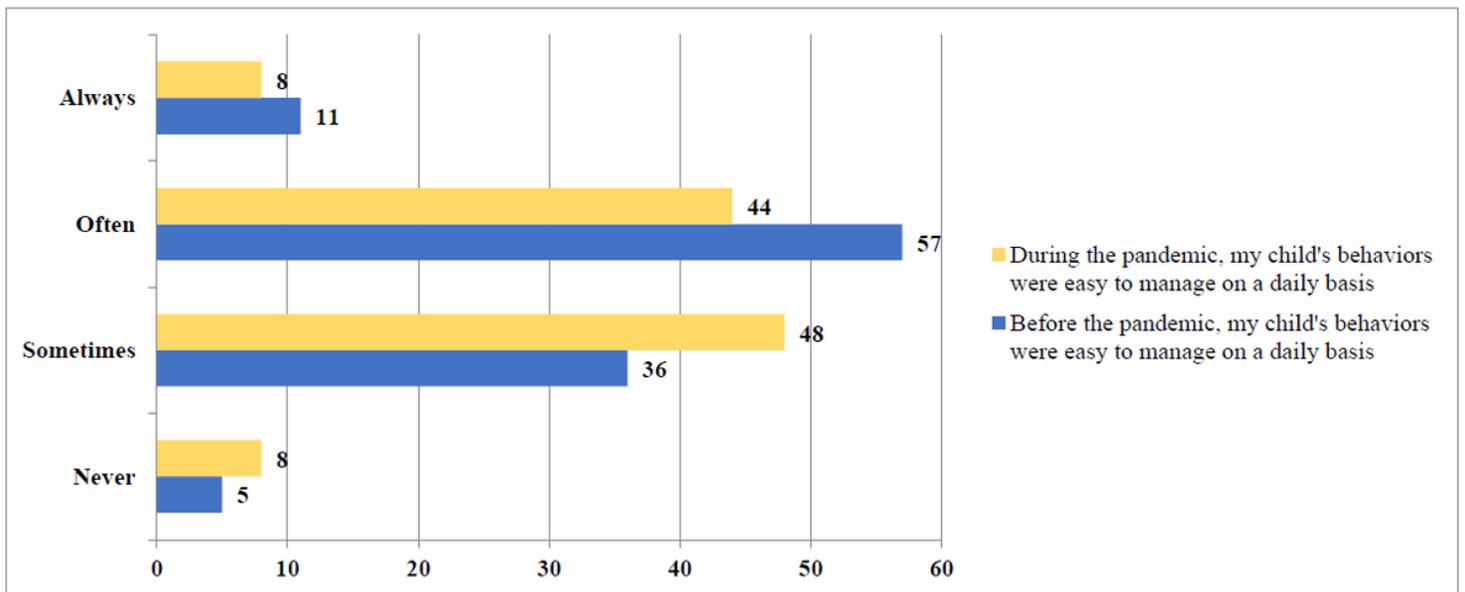


Figure 1

Differences in child's behaviors before and during the pandemic. Note. This figure shows the answers to the question: "My child's behaviors are/were easy to manage on a daily basis" during the pandemic (in yellow) versus before the pandemic (in blue). Parents answered on a four-point Likert scale, from always (always find easy to manage their child's behaviors) to never (never find easy to manage their child's behaviors).

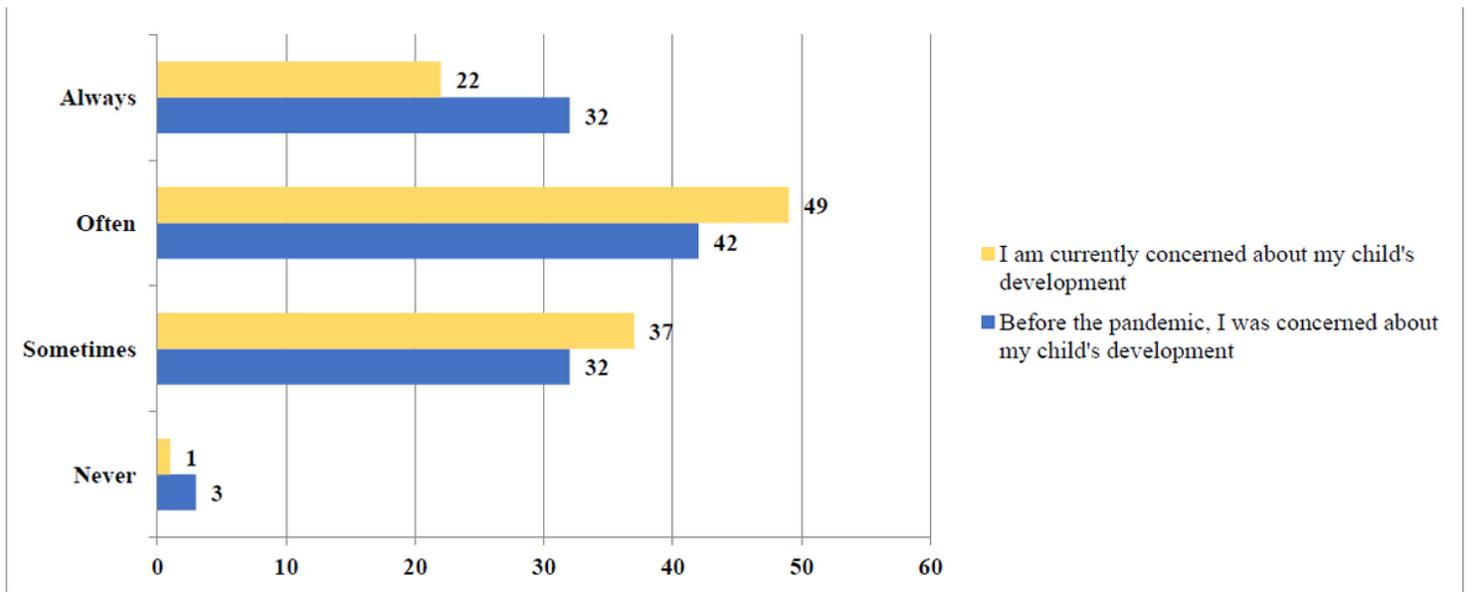


Figure 2

Differences in parents' concerns about their child's development before and during the pandemic. Note. This figure shows the answers to the question: "I am/was concerned about my child's development" during the pandemic (in yellow) versus before the pandemic (in blue). Parents answered on a four-point Likert scale, from always (always concerned about their child's development) to never (never concerned about their child's development).

Supplementary Files

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