

RESEARCH ARTICLE

“We are exhausted, worn out, and broken”: Understanding the impact of service satisfaction on caregiver well-being

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Abstract

Few studies exist that have examined the impact of service-related factors and system-level disruptions (i.e., the pandemic) on families of autistic children in Canada using large sample sizes. To address this gap, the goal of this research was to examine the impact of satisfaction with autism services on caregiver stress, controlling for important demographic variables, such as family income, marital status, and child level of support needs. The impact of navigating and accessing services on parent well-being was also explored. A total of 1810 primary caregivers of autistic children or youth living in Ontario, Canada completed a survey with both closed- and open-ended questions in the summer of 2021. A hierarchical multiple regression was conducted to examine the impact of satisfaction with autism services on caregiver stress. Open-ended responses on the survey from a subset of the sample ($n = 637$) were coded using thematic analysis to understand the impact of navigating and accessing services on parent well-being. Satisfaction with services significantly predicted caregiver stress after controlling for marital support, family income, and child level of support needs. Qualitative analysis revealed impacts of navigating and accessing services in three areas: (1) Physical, (2) Emotional/Psychological, and (3) Financial Well-being. Understanding parent perceptions of satisfaction with services can shed light on strategies for improving services that support parent well-being.

Lay Summary

The goal of this research was to examine the impact of satisfaction with autism services on caregiver stress. The impact of navigating and accessing services on parent well-being (e.g., physical health, mental health) was also explored. A total of 1810 primary caregivers of autistic children or youth living in Ontario, Canada completed a survey with both closed- and open-ended questions in the summer of 2021. A statistical analysis was conducted to examine the impact of satisfaction with autism services on caregiver stress. Open-ended responses on the survey were analyzed to understand the impact of navigating and accessing services on parent well-being. Poor satisfaction with autism services was predictive of greater caregiver stress levels. Open-ended responses revealed impacts of navigating and accessing services in three areas: (1) Physical, (2) Emotional/Psychological, and (3) Financial Well-being. Understanding parent perceptions of satisfaction with services can shed light on strategies for improving services that support parent well-being.

KEYWORDS

autism, policy, qualitative, quantitative, service satisfaction, well-being

Autism is a neurodevelopmental disability characterized by differences in social communication and interaction as well as restricted and repetitive patterns in behaviors, interests, or activities (APA, 2013). Due to the nature

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and complexity of autistic people's needs across the lifespan, there is a clear and substantial impact on caregivers and their families. Positive impacts reported in the literature include improved family relationships (Fong et al., 2021), greater empathy and prosocial behavior in siblings (Walton & Ingersoll, 2015), personal and spiritual growth in parents (Fong et al., 2021), and improved marital relationships (Lickenbrock et al., 2011).

However, families of autistic children also report higher caregiving responsibilities and mental health challenges compared to parents of typically developing (TD) children and children with other developmental disabilities (Vasilopoulou & Nisbet, 2016). Studies have shown that caregivers report elevated levels of depression (Cohrs & Leslie, 2017), anxiety (Schnabel et al., 2020), isolation (Selman et al., 2018), and financial burden (Kogan et al., 2008; Ouyang et al., 2014). In addition to these outcomes, stress has been extensively studied in the literature. This body of research suggests that various child and family characteristics may be linked to higher levels of stress. For example, families of younger children with higher levels of support needs (Manning et al., 2021), children with behavioral or externalizing problems (Olson et al., 2022), and families with lower income (Athari et al., 2013) tend to exhibit greater stress.

While this research has advanced our knowledge of child and family factors linked to caregiver stress, the impact of system-level factors, such as satisfaction with autism services, is less understood. Indeed, studies that have examined this relationship have yielded mixed findings. In one study of 190 caregivers of autistic children, researchers found no association between autism service satisfaction and caregiver stress (Rovane et al., 2020). On the other hand, a study by Ferguson, Munoz, Feerst, and Vernon (Ferguson et al., 2022) did find a significant link between satisfaction with therapies (psychotherapy, occupational services) and caregiver stress. Similar findings were also observed in a study by Moh and Magiati (2012) where it was observed that higher satisfaction with diagnostic services was associated with lower levels of stress in 102 caregivers of autistic children between the ages of 2–17 years. It is possible that the discrepancy in these findings may be due to differences in the types of therapies and services that are assessed, as well as the types of measures used to evaluate stress.

The COVID-19 pandemic created unprecedented challenges and disruptions for everyone, but especially for autistic and disabled people who rely on specialized services in their daily lives. The pandemic also exposed the fragility of support systems currently in place and the catastrophic impact that occurs when children and families are left unsupported (Charlesworth, 2020). While various lockdowns and school closures were mandated to ensure safety and stop the spread of the virus, the impact on autistic children and caregivers was profound, contributing to elevated stress and caregiver burden (Kalb et al., 2021). Specifically, Ontario schools were shut down

for a longer period of time than any other jurisdiction, creating significant stress and disruption to daily routines for families (Gallagher-Mackay et al., 2021). Research exploring the impact of the pandemic on families of autistic children has revealed that while access to services was already precarious pre-pandemic, the significant lack of both formal and informal supports during this time created crisis in many households (Alhuzimi, 2021; Colizzi et al., 2020; Manning et al., 2021). These findings suggest that caregiver stress and well-being may vary more as a function of system- or service-related factors rather than child or family demographic variables, which has previously been suggested (Hodgetts et al., 2017).

With the exception of a handful of studies using small sample sizes (Moh & Magiati, 2012; Rovane et al., 2020), few studies exist examining the link between satisfaction with government-funded services and caregiver stress. Additionally, while the majority of the research has relied upon quantitative measures to examine the impact of caregiving responsibilities on a range of caregiver outcomes, few studies exist examining the specific impact of navigating autism services on caregiver well-being using qualitative approaches. In light of these gaps, the goals of the study were as follows:

1. Quantitatively examine the impact of satisfaction with autism services on caregiver stress, controlling for important demographic variables including family income, marital status, and child level of support needs, to address the lack of research assessing service-related factors on family outcome.
2. Qualitatively explore the impact of accessing and navigating services on parent well-being to address the scarcity of studies examining in-depth accounts of parent experiences related to obtaining services.

METHODS

Study setting

In Ontario, where our study took place, families of children who have received an autism diagnosis may obtain funding through the Ontario Autism Program (OAP). The OAP has experienced several major overhauls over the past decade in the wake of government changes and parent-led protests (CBC, 2019; The Canadian Press, 2019). During the time of study (summer 2021), in an effort to clear years-long backlogs to receive support, the government gave direct funding in set amounts to most eligible families. Children 5 years and under were given a funding disbursement of \$20,000 toward eligible intervention services (e.g., behavioral, occupational therapy, speech/language therapy, respite, equipment). Most children between the ages of six and 18 years were given a budget of \$5000 in direct funding per year toward similar services. A subset of families who transitioned in from an earlier iteration of the program received needs-based

behavioral therapies during this period, while others started to transition into newly developed program streams on top of their fixed allocation budgets (e.g., school readiness programs and caregiver mediated early intervention training). As of 2022, a new OAP has been rolling out, with funding determined by a combination of age and need (Government of Ontario, 2019). This context is important to note, in particular that families were at different stages and accessing different iterations of the OAP, which could have implications for their access to resources and support services.

Participants

A total of 1810 Ontario caregivers completed a survey with both closed- and open-ended questions. Parents of autistic children were recruited primarily via Autism Ontario, which has a database comprised of families of autistic people. Inclusion criteria specified that parents had a child aged 17 years or younger diagnosed with autism. The survey was available online in both English and French between June 30–July 23, 2021.

The majority of our sample respondents were mothers (90%). The average family income was \$89,446.79, which is lower than the provincial average income of \$97,856 (2016 Ontario Census). Twelve percent of families lived in a rural region and 31.8% lived in medium or smaller population centers. Demographic information for parents and their families are provided in Table 1. The age range of the autistic child that parents reported on was between 1 and 17 years ($M = 8.9$; $SD = 4.1$).

Measures

The researcher-developed survey was created in collaboration with our community partners from Autism Ontario and researchers with complementary areas of expertise (see acknowledgements). The survey was then pilot tested with members of the autism community, including parent caregivers from diverse socioeconomic, ethnic, gender, geographic, and neurodivergent (autistic) backgrounds. Feedback on the survey's content, language, comprehensiveness, clarity, and accessibility was provided during this stage. Once their input and revisions were incorporated, a final round of parents and researchers evaluated the online format in Qualtrics to ensure the survey was user-friendly and had a logical flow.

The purpose of the survey was to gather the information from primary caregivers (almost entirely parents) of Ontario children or youth with an autism diagnosis about their recent experiences in the context of the COVID-19 pandemic. Survey topics were chosen to address gaps in our knowledge specifically around the impacts of service-related factors and system-level disruptions (i.e., pandemic) on families. Examples of areas covered in the survey

TABLE 1 Family demographics.

Demographic information	Frequency (%) (<i>N</i> = 1810)
Caregiver gender	
Male	170 (9.4)
Female	1630 (90.1)
Non-binary	1 (0.1)
Family and Parenting Situation	
Parent with partner support (e.g., married)	845 (46.7)
Parent with minimal/without partner support	965 (53.3)
Ethno-cultural background	
Indigenous (e.g., First Nations, Métis, Inuk (Inuit))	60 (3.3)
Arab	28 (1.6)
Black	108 (6.0)
Chinese	99 (5.5)
Southeast Asian (e.g., Vietnamese, Thai, Cambodian, Laotian, etc.)	29 (1.6)
South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)	153 (8.5)
Filipino	63 (3.5)
Japanese	6 (0.3)
Korean	5 (0.3)
West Asian (e.g., Iranian, Afghan, etc.)	15 (0.8)
Latin American	53 (2.9)
White	1132 (62.5)
Highest level of education	
Less than grade 8	3 (0.2)
Grade 8	4 (0.2)
Some high school	45 (2.5)
High school diploma or equivalent	125 (6.9)
Some college or university	235 (13.0)
College, CEGEP or other non-university certificate or diploma	547 (30.2)
University undergraduate degree	390 (21.6)
University graduate degree	430 (23.8)
Child's gender	
Female	409 (22.6)
Male	1362 (75.3)
Non-binary/Questioning Gender	31 (1.7)
Perceived level of child support needs	
Requires very substantial support	412 (22.8)
Requires substantial support	518 (28.6)
Requires support	880 (48.6)

included: (1) child education; (2) autism services and supports; (3) child recreation; and (4) caregiver well-being. The focus of the current study is on the sections related to autism services and caregiver well-being. Satisfaction with services, caregiver stress, and demographic questions were examined using the following measures outlined next.

Satisfaction with services

Parents were asked to rate on a Likert scale ranging from 0 (*None of the child's needs were met*) to 6 (*Most or all of the child's needs were met*), the extent to which the OAP has met the therapy and support needs of the child over the past year. Examples of services from the OAP that families could have been receiving included behavioral therapy, speech language therapy, occupational therapy, respite, and technology/equipment.

Stress

Parents completed the Brief Family Distress Scale (BFDS; Weiss & Lunskey, 2011), which is a one-item scale with ten statements ranging from 1 (*Everything is fine, my family and I are not in crisis at all*) to 10 (*We are currently in crisis, and it could not get any worse*). Respondents select the statement which best describes where they and their families are currently in terms of crisis. Previous work (Benninger & Witwer, 2017) has demonstrated that the BFDS is a psychometrically sound scale with good construct, content, and convergent validity with other lengthier and more widely used scales such as the 21-item Caregiver Strain Questionnaire (CGSQ; Brannan et al., 1997).

Demographic questions

Participants were asked to provide sociodemographic information on themselves (e.g., gender, education level), their child (e.g., age, gender, level of support needs), and family (e.g., family income, race/ethnicity).

Impact on navigating services on parent and family well-being

The three open-ended questions which were qualitatively analyzed were as follows:

1. Can you expand on your response to the Brief Family Distress Scale?
2. To what extent do you think your physical health has been affected by the challenges of accessing and navigating autism-related services and supports?
3. To what extent do you think your mental or emotional health has been affected by the challenges of accessing and navigating autism-related services and supports?

Procedure

The protocol for this study was reviewed and approved by the Institution's Research Ethics Board in Ontario,

Canada. Parents who met inclusion criteria for the study provided their consent and proceeded to the main survey questions. There were two parts to the survey, each taking between 15 and 25 min to complete. Upon completion of the survey, respondents were offered the chance to enter for a draw prize of: one of fifteen \$50.00 prizes for completing Part 1 only, or one of fifteen \$100.00 prizes or a \$500 grand prize for completing both Parts 1 and 2.

Analysis

Quantitative analysis

Data analysis was conducted using SPSS, Version 24. Descriptive statistics for each scale were used to characterize the sample. Bivariate Spearman's correlations were used to examine the relationships between child level of support needs, marital support, family income, satisfaction with the OAP, and stress levels. A hierarchical regression was used to determine whether the main predictor variable of interest (e.g., satisfaction with services) could explain a significant amount of variance in stress (e.g., score on the BDI Scale) after controlling for demographic variables such as family income, marital status, and child level of support needs. The data were inspected for non-normality, unequal variances, and multicollinearity. Normality was checked through visually inspecting the distributions and examining the skewness and kurtosis values. Variance inflation factors (VIF) were under 2.0 for each variable, indicating that there was likely no multicollinearity among study variables.

Qualitative analysis

Open-ended responses on the survey evaluating the impact of navigating and accessing services on parent well-being were compiled into an Excel spreadsheet (Version 16.73, Microsoft Inc.). Thematic analysis guided by Braun and Clarke (2012), was conducted to analyze the three open-ended questions on the survey evaluating the impact of navigating and accessing services on parent well-being. The first author, a neurotypical researcher with over 10 years of work and research experience in the autism and developmental disability field, read through the entire dataset of open-ended responses to familiarize herself with the data and generate a list of potential codes. These codes were identified semantically by summarizing the participant's overall response and latently through interpreting the overall meaning of the response. The list of codes that were generated during this stage were discussed in meetings with the research team including the other authors and two undergraduate research assistants. These codes were revised, refined, and collated using an iterative process. Codes that were deemed similar or redundant were grouped together to create

overarching themes and subthemes. The finalized list of codes was used by two research assistants to consensus code all of the responses. Inter-coder reliability using percent agreement (Roaché, 2017) yielded a high reliability (97.8%) between the coders. Discussion among the authors led to further refinement of the themes to identify patterns across the dataset. Related themes and subthemes were further consolidated, and those deemed not meaningful or significant in addressing the research question were removed.

RESULTS

Quantitative results

Descriptive statistics for the main outcome variables are presented in Table 2. The first model of the regression analysis, which controlled for marital support, family income, and child level of support needs, accounted for 7.9% of the variance in stress levels ($F(3, 1806) = 52.59, p < 0.001$). The second model, which controlled for satisfaction with autism services, was significant ($R^2 = 0.11, F(4, 1805) = 56.63, p < 0.001$), and accounted for an additional 3.1% of the variance in stress above and beyond Model 1 ($\Delta F(1, 1805) = 63.30, p < 0.001$). The associated regression coefficient for satisfaction with OAP services was significant ($\beta = -0.40, p < 0.001$). In other words, greater satisfaction with OAP services predicted lower levels of caregiver stress. See Table 3 for a summary of both models at each step.

Qualitative findings

A total of 637 participants provided responses to either of the three open-ended questions on the survey. Three themes related to impacts navigating and accessing

services were identified in the open-ended responses on the survey, those pertaining to: (1) physical, (2) emotional/psychological, and (3) financial well-being. Several subthemes emerged for each theme. The frequencies that each subtheme were mentioned by parents are summarized in Table 4.

Physical well-being

Parents often described how challenges accessing services and experiencing gaps in their child's care negatively affected their physical health and well-being. For example, they commonly discussed having fewer hours of sleep, poor quality sleep, or feeling tired during the day. Sleep problems were often attributed to the stress of navigating services and time spent advocating for their child:

I don't think that I have had a good night's sleep since 2010 when I first learned of my

TABLE 4 Summary of respondents identifying each theme.

Theme and subtheme	Frequency (%) <i>N</i> = 637
Physical well-being	
Tiredness and Fatigue	63 (9.9)
Health Problems, Illness	91 (14.3)
Unhealthy Behaviors (e.g., drinking, diet)	105 (16.5)
Emotional/psychological well-being	
Depression	47 (7.4)
Anxiety	68 (10.7)
Financial well-being	
Financial Hardship, Poverty	112 (17.6)
Decreased Work Productivity, Increased Absences	19 (3.0)

TABLE 2 Scale descriptive statistics.

Survey item	M (SD)	Observed range	Theoretical range
Brief family distress scale	4.28 (1.52)	1–10	1–10
Satisfaction with services	2.82 (1.52)	1–6	0–6

TABLE 3 Satisfaction with the OAP services predicting caregiver stress (*N* = 1810).

Variable	Model 1				Model 2			
	<i>B</i>	<i>SE B</i>	β	<i>P</i>	<i>B</i>	<i>SE B</i>	β	<i>P</i>
Marital support	−0.43	0.08	−0.12	<0.001	−0.38	0.08	−0.11	<0.001
Family income	0.00	0.00	−0.07	0.002	0.00	0.00	−0.07	0.002
Child level of support needs	0.50	0.05	0.23	<0.001	0.46	0.05	0.22	<0.001
Satisfaction with OAP services					−0.40	0.05	−0.18	<0.001

child's autism diagnosis and entered the realm of parents with special needs children who, as physically strong as we all are, endure physical punishment from the stress placed upon us as a result of spending our time advocating for our children 24/7.

Parents frequently mentioned developing health problems or experiencing worsened symptoms. Examples of health conditions shared by parents included cardiovascular disease, hypertension, arthritis, migraines, and chronic pain. For some of these parents, these health issues were worsened due to limited access to services and feeling constant worry and hypervigilance about their child's future. Parents also frequently described the inextricable link between physical and emotional well-being, for example two parents shared:

I can't stop worrying about my child's future and loss of precious developmental time waiting for services. I have suicidal thoughts, stress, headaches, digestive issues all related to the stress of caregiving and advocating for my child.

I have chronic health issues due to the stress of managing my child who needs constant programming. This has caused physical pain.

During the pandemic and various lockdown periods, parents reported feeling overwhelmed and "pouring from an empty cup". As a result, parents described developing unhealthy behaviors to cope, such as smoking, drinking, over- or under-eating, and skipping exercise. For many of these parents, their physical health declined due to a lack of self-care and having the majority of their time and energy spent caregiving and navigating services:

I have stress, anxiety, and feel physically unwell. The system is broken and is incredibly hard on parents to navigate and afford.

My physical health has declined. I am a human trampoline right now with no time to care for myself.

Emotional/psychological well-being

Parents frequently shared experiencing elevated levels of depression and anxiety due to the loss of services and their informal support networks during the pandemic. In extreme cases, where parents felt that they could not care for their child with the limited supports available, some considered giving up their children:

I have depression and suicidal thoughts. The lack of help has led me to think of giving up

my children. It has also created high levels of stress in our marriage.

Families on waitlists for services and families with an autistic child in a transition period reported an increasingly difficult time with their mental health during the pandemic. Two parents articulated:

My mental health has been on a constant decline since we have been on the OAP waitlist for 3 years. The lack of supports for my child and myself have caused me to have suicidal thoughts. I have spent time in an inpatient psychiatric hospital before the pandemic and COVID has made our crisis situation so much worse. It takes a village to raise a child with a disability and our village was taken away for over a year.

I received the news that my son met criteria for a diagnosis of ASD in August of 2020. I can't think of a time in my life where I have felt more isolated. I felt very alone. When it came to thinking about my son entering the school system I felt so overwhelmed at the idea of where to begin to support that transition. It felt a lot like standing on an island shouting for help and hoping someone hears you. But not only that they hear you, that they understand you. Since last August I have been shouting, but only a handful of people have heard and truly understood what it has been like and that is incredibly isolating.

Many parents emphasized the importance of improving access to mental health services and recognizing the emotional and psychological toll on parents to simultaneously cope with a new diagnosis and obtain services across fragmented systems of care:

The funding submission forms need to be simplified. I called several times for assistance, which also proved frustrating. Many tears were shed filling out these forms and stressing if I had done it correctly.

I have never struggled with depression in my life until my daughter's diagnosis. I have PTSD from her seizures. Special needs parents are not OK, not even a little bit. I speak to many of them online and we are exhausted, worn out, and broken.

It is important to have somebody check in on the caregivers as well. Taking care of kids with special needs 24/7 takes a toll on the person physically, mentally, and emotionally.

Financial well-being

Parents often shared the financial consequences of providing care for their autistic child and the out-of-pocket costs related to accessing various therapies for their child:

We are a family of four on a single income. Money is tight, especially after the [autism] diagnosis where we have to spend more on therapies. Me and my spouse worry every time how much longer we can afford the much-needed therapies our ASD child needs.

Parents frequently discussed how costs have accumulated over the years contributing to significant financial burden and housing instability. For some caregivers with underlying health conditions or families experiencing poverty, barriers accessing and affording services seemed insurmountable:

I am on disability with an autoimmune disease and the poverty is all-encompassing. They provide \$781 monthly for shelter for myself and my son, but no one can afford to rent an apartment anywhere for that amount. I end up having to spend the measly amount remaining to just put a roof over our heads. I cannot support my son's needs with this. It is depressing...and impossible to focus on my son's needs when we are struggling to NOT be homeless. If our basic needs were met, I would be able to focus on my son's needs.

A number of parents mentioned having to give up their careers and employment to provide care for their child. For most of these families, this tended to be women who were sacrificing their careers; as these mothers shared:

I do not feel financially secured and empowered as being a mother should be. I sacrificed all working opportunities to keep the kids well and going.

The fact that I was at home to care for my son from birth I know improved his life. I was able to be there for him and advocate for him always. We managed on one income but I am left in a position where I'm dependent on my husband for money and have no savings of my own.

When we had our kids, I planned to go back to work when they went to school full time. Our son is nine and is not in school full time

and has needs that before/after care can't manage so I am unable to work at all.

DISCUSSION

The first objective of the study was to examine the impact of satisfaction with autism services on caregiver stress, controlling for important demographic variables including family income, marital status, and child level of support needs. In contrast to a pre-pandemic study by Rovane et al. (2020), we observed a significant link between service satisfaction and caregiver stress. On the other hand, our results were consistent with research conducted during the pandemic by Ferguson et al. (2022), which found that lower satisfaction with behavioral therapies was linked to greater emotional dysregulation in caregivers. Similarly, our findings are strengthened by the results of a report by (McLaughlin & Schneider, 2019) which found that better caregiver mental health outcomes were linked to higher satisfaction with the child's school affairs (e.g., safe and supportive education environment) and receiving behavioral services. These results address a significant gap in our understanding of how service-related factors impacted parent well-being in Canada during the pandemic. The implications of the findings that satisfaction with the OAP predicted caregiver stress are significant and highlight the critical role that government programs have on the well-being of families of autistic children. The findings also emphasize the importance of community engagement and collaboration with parents and autistic people in the design, implementation, and evaluation of programs that directly impact their lives.

Another aim of this study was to explore the impact of navigating services on parent well-being. The findings revealed three categories of caregiver and family impacts relating to: (1) physical, (2) emotional/psychological, and (3) financial well-being. Although these categories are presented as distinct themes, it is important to note that these elements are often interconnected in a dynamic and reciprocal manner, emphasizing the need for a comprehensive and holistic approach that addresses all aspects of an individual's well-being. Consistent with previous research, caregivers of autistic children experience poor quality sleep, tiredness, and declines in physical health (Hartley et al., 2018; Mihaila & Hartley, 2018). Extending these findings, our results have linked poor sleep and physical health specifically to the challenges navigating and accessing services for their child. While the bulk of the research has primarily focused on anxiety and depression outcomes in caregivers, fewer studies have examined the physical health outcomes linked to navigating and accessing services. In the current study, parents reported developing health conditions, such as arthritis and migraines, and experiencing worsened symptoms related

to hypertension and chronic pain, due to elevated stress around obtaining services for their child. These findings underscore the importance of supporting caregivers in their role, as there are clear perceived health consequences for the caregiver, and as a result, also for their children and family.

Similar to previous findings (Bromley et al., 2004; Hodgetts et al., 2017), parents in the current study also reported worsened anxiety and depressive symptoms associated with satisfaction with services and availability of supports. Additionally, our results also converge with previous research by Christi, Roy, Heung, & Flake, (Christi et al., 2022), which found that poor access to respite was linked to mental health challenges for caregivers. However, a novel finding in the current study was that a number of parents reported having suicidal thoughts and feeling pressured to give up their children due to the lack of services for their child and supports for their family during the pandemic. These findings shed light on the feeling of crisis and desperation experienced by some families when they are cut-off from previously held supports or do not receive services and supports at all.

The findings related to financial impacts were similar to other studies demonstrating the high out-of-pocket costs, debt, and negative impacts on employment related to accessing and navigating autism services for their child (Brewer, 2018; Hodgetts et al., 2014; Kalb et al., 2021; Kogan et al., 2008; Looman et al., 2009). However, it is likely that the financial impacts of providing care to an autistic child were exacerbated during the pandemic due to mass lay-offs and school closures. It was not uncommon for parents in the current study to report housing difficulties and living on the brink of poverty due to high costs for various services and therapies. Drawing these experiences together, our qualitative findings have addressed a key gap in the literature by providing detailed insights and in-depth accounts from parents that capture the complexity of accessing and navigating services and how these experiences have impacted their well-being.

Moreover, responses on the survey frequently indicated that parents, most often mothers, were sacrificing their careers and employment to care for their child and obtain services, which many reported to be a full-time job in itself (see also Maich et al., 2019). On top of caregiving, our research found that parents, mainly mothers, on average spent 5.9 h per week advocating and 9.3 h navigating services for their children, or a total of 15.2 h per week (Gentles et al., 2022). When children with specialized needs are not adequately supported in services, or even reliably accommodated in school (which many parents noted was the case), caregivers may have no choice but to quit or downgrade their employment, further compounding financial pressures. Thus, it is important for policies to provide financial supports for caregivers, who are most commonly women, given the specialized care that they provide to their families and society at large, and the significant amount of time they

spend not only caring for, but also advocating and navigating services for their children. Essentially, mothers are typically the invisible safety net when all other social and educational services fail their children, but doing so comes at great cost to their physical, psychological, and financial well-being.

The current study had a number of limitations that warrant caution when interpreting the results. The majority of respondents being mothers may limit the generalizability of the findings to fathers (we asked for the *primary* caregiver to complete the survey). Future studies may need to use alternative strategies to recruit fathers, such as explicitly inviting fathers rather than “parents” or “caregivers” on research flyers and advertisements. The study is also based on a convenience sample; therefore, the results may be subject to selection bias and not generalizable to caregivers as a whole. Another limitation is the cross-sectional design of the research, whereby causality is unknown. It is possible that rather than satisfaction with autism services predicting caregiver stress, stress may be impacting their satisfaction with these services. Additionally, since the study focus was on pandemic effects, the results should be interpreted with caution considering the potential lack of generalizability to non-pandemic responses. Future studies using longitudinal designs are needed to confirm the direction and strength of this link over time. This will also shed light on how perceptions of and access to services and supports fluctuate over time and impact caregiver and family well-being. Another limitation is the reliance on a single item question to assess service satisfaction and caregiver stress. Although this approach may reduce participant burden, especially for caregivers who have limited time, it may not fully capture the complexity of both constructs. Future studies are needed to confirm these findings by using more comprehensive assessment and measurement tools. A final limitation of the study relates to the qualitative findings which are hypothesis-generating, not hypothesis-testing, and therefore further research is needed to more rigorously test the themes derived from the qualitative component of the study.

CONCLUSION

Our quantitative findings indicated that satisfaction with autism services was predictive of caregiver stress, after controlling for important demographic factors such as marital support, family income, and child level of support needs. Analysis of the open-ended responses revealed impacts of navigating and accessing services in three areas: (1) Physical, (2) Emotional/Psychological, and (3) Financial well-being. Examining the impact of navigating and accessing services on caregiver stress and well-being can help identify strategies for improving services and supports to help families cope during stressful times and in the event of future public health emergencies.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethics approval was obtained from the University Research Ethics Board, and informed consent was obtained from all parent participants included in the study.

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