



Parenting a Transitional Age Youth with Autism: Mental Health and Relational Experiences

Samantha O’Leary, Priscilla Burnham Riosa, Tricia van Rhijn and John Beaton

Abstract

Purpose: This study explores the lived experiences of parents of transitionally aged, autistic youth (16-24), regarding their mental health and wellbeing, and their parent-child relationships. A prominent gap in the literature exists surrounding autistic youth of this age group, let alone their parents. **Methods:** With a focus on parents who live in Ontario, Canada, this qualitative study uses open-ended surveys ($n = 19$) to explore the mental health and relational dynamics between parents and their transitionally aged, autistic youth, both prior to and during the COVID-19 pandemic. **Results:** Thematic analysis of the survey responses suggests latent themes of: *“I have good times and bad”*: *The importance of external factors* and *Parenting variability: Ongoing learning and an uncertain future*. Results indicate complex and varied experiences of parents, reflecting strengths and challenges at multi-systemic levels. Participants reported that the presence of external supports, including paid and co-caregiving support positively affected their mental health and parent-child relationships, while absence of supports were detrimental. **Conclusion:** Complex interactions of internal and external factors influence parental mental health and wellbeing and the relationships they have with their autistic youth which have been further complicated by the COVID-19 pandemic. Availability of non-judgemental, formal and informal supports are encouraged to enhance the mental health and caregiving experiences of parents of transitional aged, autistic youth.

Keywords: Transitional age youth; Autism; Parenting; Mental Health; Parent-Child Relationship

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Introduction

In contemporary western culture and industrialized societies, adolescence can be understood from a variety of perspectives including biological, sociological, and cognitive frameworks. Several eminent scholars have explored adolescence in either developed or developing countries including Erikson, Piaget, Kohlberg, Levinson, Mead, and Keniston (Arnett, 2000; Roopnarine & Gielen, 2016). While the general literature on adolescence is diverse, limited research exists surrounding the transitional age of development. Even less is known about this developmental stage for autistic youth, which may be due in part to the lack of clarity around the distinct age parameters of this population. How parents navigate their relationships with their autistic youth¹ and how these parenting demands influence their mental health and wellbeing is also unclear.

The developmental period between adolescence and adulthood can be associated with marked change and challenge. Arnett (2000) proposed the term emerging adulthood as the conception of this developmental stage wherein an individual may not neatly fit or identify as either an adolescent or an adult. This stage, focused on individuals between the ages of 18-25, reflects a period of identity formation and the exploration of life trajectories. This view is consistent with Erikson's (1968) propositions that identity formation is the developmental goal in the stage of adolescence and that industrialized societies can foster a period of prolonged adolescence in which individuals experiment with their ambiguous societal roles (Arnett, 2000; Reifman et al., 2007). Within this period, individuals tend to focus on their education and vocational opportunities, rather than marriage and family development (Arnett, 2004; Reifman et al., 2007). Arnett's (2000; 2007; 2014; 2015) conception of emerging adulthood is problematic, however, for some youth with developmental disabilities, including people on the autism spectrum, such as his assertion of independence as a marker of adulthood.

In acknowledging that limited research exists for transitional age, neurotypical youth, it comes as no surprise that there is a paucity of literature surrounding transitional age youth with autism or a developmental disability. Wilens and Rosenbaum (2013) briefly mention transitional age youth with autism in their paper on child and adolescent psychiatry, noting that skill development during these years is a critical, though under-recognized, opportunity for development and improvement. Other research in this area describes poorer quality of life for autistic youth and those with challenging behaviours, such as aggression and self-injury (i.e., Biggs & Carter, 2016), educational outcomes and vocational readiness (i.e., Lee et al., 2018; Westbrook et al., 2014) and how the tumultuous developmental stage of puberty particularly affects autistic youth (Picci & Scherf, 2015). Other areas that have received some attention in the literature include the strengths of transitional age youth on the autism spectrum reported by parents (e.g., Carter et al., 2015), siblings (e.g., Carter et al., 2020), the importance of person-centered planning in the transition process and successful markers of transitions (see Chun et al., 2022).

Parenting a transitional age youth is unique, and perhaps even more so for transitional age youth on the spectrum. This literature, albeit limited, offers support to the ongoing nature of parental relationships and discusses how roles and influence may change throughout the life

¹ There has been significant discussion around person-first versus identity-first language throughout the literature on disabilities as well as specific to autism. Consistent with Vivanti (2020), throughout this paper we alternate between the two, and neutral statements to consider the diverse preferences of our participants.

course. Test et al. (2014), for example, discuss the importance of parental relationships for youth with autism, commenting that parents typically provide care and support throughout life, but this is particularly salient during the transitional process as youth with autism often experience difficulty coping with change. Russa et al. (2015) also note how parents are generally life-long advocates for their children, which differs from parents of non-autistic and non-disabled children. These parenting demands and subsequent mental health impacts for parents of autistic children are still relatively new areas of study in need of deeper exploration. Canadian research on the mental health impact on parents of children with autism revealed that a majority of parents endorsed their overall mental health as either very poor (42%) or extremely poor (29%) (McLaughlin & Schneider, 2019). Open-ended responses in the Laurier Autism Research Consortium's report on *Autism in Ontario* revealed that parents experience stress with planning, lack of respite, relationship stress, waiting for services, aggressive behaviours, and difficulties with schools, therapists, and society (McLaughlin & Schneider, 2019).

Overall, emerging adulthood or the transitional age of development, is a period characterized by tremendous growth, bringing about incredible opportunities, yet many uncertainties. For transitional age youth on the autism spectrum, this developmental stage can be particularly challenging due to the effects of puberty, emphasis on vocational readiness, lack of transition planning and resources, and possible behavioural difficulties. Parenting during this developmental stage can also be challenging for those reasons, in addition to relationship stressors, services ending for their child, and limited mental health resources for these caregivers, among others. Thus, the purpose of this study was to explore the lived experiences of parents of transitional age youth (ages 16 to 24) with autism using thematic analysis to understand parental mental health and their experiences of parenting a transitionally aged, autistic youth. The guiding question of this qualitative research study was: what are the experiences of parenting a transitional aged youth with autism? Based on the limited research surrounding the transitional age of development and the existing literature on parent-child relationships of parents of autistic children, we answered the following research questions:

1. How does a parent's mental health influence their raising of a transitional aged youth with autism?
2. What are the parent-child relationships between parents and their transitional aged youth with autism?

These questions were also contextualized given the COVID-19 pandemic, which was at its height during data collection. Understanding the factors that influence parental mental health and their relationships with their child at this particular developmental stage, during and outside of a pandemic, can open the door for future research, policy and program development, ultimately benefitting the families of autistic youths.

Materials and Methods

Participants

Participants ($n = 19$) were parents or primary caregivers of a transitional aged youth, a youth between the ages of 16 to 24 with autism. Proof of formal diagnosis for their child was not required. Age restrictions reflected that of the age of the youth, rather than the parent/caregiver to align with the transitional age of development. Participation was not restricted to the biological parent(s) of the transitional age youth. Participants that had more than one transitional age youth on the autism spectrum were permitted to complete one survey per child, though no participants appeared to submit separately when they had more than one autistic child. Demographic characteristics were collected for both the parents and the transitional age youth; however, it should be noted that the youths' characteristics were reported by the caregivers. Demographic characteristics for parents are summarized in Table 1 and the characteristics of their transitional age youth are summarized in Table 2. The mean age for parents was 51 years ($SD = 5.01$, Range = 41-60) with the majority of respondents identifying as female (84.2%). Nearly three-quarters (73.7%) of parents identified as White, and nearly all had either a post-secondary certificate, diploma, or degree (94.7%). All participants lived in Urban regional locations (36.8% Halton, 21% Peel, 10.5% Guelph/Wellington, 10.5% Kitchener/Waterloo, 5.3% Toronto, 5.3% London-Middlesex, 5.3% Windsor/Essex) and over two-thirds (68.4%) were employed on a full-time basis. The majority of parents identified as being married (57.9%) and having an annual household income of over \$100,000 (gross; 42.1%). The number of children they had ranged from 1 to 4.

Procedure

Online recruitment through social media (i.e., Autism Facebook groups, Instagram) and internal postings on developmental service websites (e.g., Autism Ontario, Central West Specialized Developmental Services, Community Living Dufferin) were conducted. A written description of the study and an informational flyer including the link to the Qualtrics survey and contact information for the principal and student investigators were shared. The survey launched on December 1, 2020 and closed on January 26, 2021, taking an average of 30 minutes to complete. At the end of the survey, participants provided an email address to be entered into a draw for a \$25 electronic gift card and were asked whether they consented to be included in a follow up interview. A total of 9 follow up interviews were conducted. Ethical approval of this study was obtained through the University of Guelph institutional research ethics board, prior to data collection (REB #20-06-018).

Measures

Online Survey: After the demographic portion of the survey, a series of three sections

asked for open-ended responses pertaining to parent mental health, parent-child relationships, and co-parenting relationships, respectively. There were approximately four questions within each of these parts. The Family Stress and Coping Interview (FSCI; Nachshen et al., 2003) and the Co-Parenting Relationship Scale (CPRS; Feinberg et al., 2012) were used as guiding frameworks in the development of the survey questions. The FSCI explored experiences of stress and coping for parents of transitional age youth with autism. This measure was developed for families of individuals with developmental disabilities and is a beneficial measure for a number of reasons including: its responsiveness to lifespan perspectives, involvement with families in its original conception, and its anti-pathologizing approach for understanding successes in coping and adaptation for families (Nachshen, et al., 2003). In its original conception, this measure explored the mental health and coping of parents and caregivers, and used both qualitative (5-items; open-ended responses) and quantitative research methods (23-items). The CPRS (Feinberg et al., 2012) was used as a guide for the relationship questions, adapted to reflect wording of co-parenting transitional age youth with autism. The original 35-item measure demonstrated both reliability and stability, and the revised 14-item brief version was strongly associated with the original conception (Feinberg et al., 2012).

Parent Mental Health. This section of the survey was comprised of six open-ended questions to better understand parental mental health. The purpose of these questions was to describe both the strengths and challenges observed in relation to the parent's mental health and wellbeing, any coping resources accessed, and how the parent's own mental health influences their parent-child and co-parenting relationships. For example, mental health related questions included *"how would you describe your mental health and wellbeing"*, *"what strategies do you use to support your mental health and wellbeing"*, and *"how does your mental health influence your relationship with your transitional age youth."*

Parent-Child Relationships. There were four open-ended questions developed to understand the relationship between the parent and their transitional age, autistic youth. The purpose of these questions was to explore meaning, role expectations as a parent, relationship changes over time, and qualities about the specific parent-child relationship. For example, the open-ended questions about the parent-child relationship included *"what does being the parent of a transitional age youth with autism mean to you,"* *"how has your parenting role evolved throughout your child's development,"* and *"what has been your most meaningful experience as a parent."*

Co-parenting Relationships. There were four open-ended questions about the co-parenting relationship. The purpose of these questions was to understand with whom the parent shares caregiving responsibilities, the progression of that caregiving relationship throughout the child's life, and the strengths and challenges associated with co-caregiving. For example, open-ended questions included *"who is your co-parent/co-caregiver (e.g., nanny, current, or ex-partner, your parent, etc.),"* *"how has your relationship evolved throughout your child's development,"* and *"in what ways does your co-parent/co-caregiver provide you with support."*

Data Analysis

The demographic information of the participants gathered through the online surveys was analyzed with descriptive statistics, using the IBM SPSS Statistics for Mac (Version 26.0). Thematic analysis was used to evaluate the latent content of the surveys and to categorize themes. Coding of the data from the online surveys was conducted using the qualitative data analysis computer software program, NVivo for Mac (released December 2020) and followed Braun and Clarke's (2013) six-step analytic framework. Where possible, participants' own words were used to identify and categorize themes to capture the lived experience and vocabulary of these parents.

Data Quality: Sufficient data for a small, phenomenological qualitative research project could include between three and six interviews and/or 10-20 surveys (Braun & Clarke, 2013). Saturation in qualitative research has been a seemingly contentious issue as there have been inconsistencies in its application across methodologies. Malterud et al. (2016) suggest that the concept of "information power" is a better guide for adequate sample size in qualitative research than would be saturation, as sufficient samples are dependent on: the aim of the study, sample specificity, theoretical application, quality of dialogue, and the analysis strategy. As the online surveys used in this study contained open-ended questions eliciting lived experiences of mental health and relationships, they were treated as if they were interview transcripts. As such, a sample size of 19 participants was considered appropriate for this project. Research focusing on open-ended survey questions indicates that response length, latency, and interpretability of responses should be examined as more comprehensive quality indicators than any one of those factors on their own (Schmidt et al., 2020). Further, Schmidt et al. (2020) reported that respondents with higher education and motivation typically provided higher quality open-ended survey responses. As nearly 95% of our sample completed some post-secondary education and given the gap in research surrounding transitional age autistic youth, we believe our participants were particularly motivated to offer quality responses to our open-ended survey questions.

To generate credible and trustworthy data, we used theoretical triangulation (Cronin-Davis et al., 2009), peer debriefing, researcher reflexivity, and thick description (Brantlinger et al., 2005). Theoretical triangulation involves multiple perspectives to understand a phenomenon; here we used symbolic interactionism (Blumer, 1969) and family systems theory (Bowen, 1978) to guide our understanding of parenting a transitional age, autistic youth. We also leveraged author J.B.'s lived experience as the father of a disabled teenager to provide a peer debrief of critical feedback on the analysis and interpretation of our results. Researcher reflexivity was also critical to acknowledge our potential biases and assumptions during the analytic stage. For example, one of the authors (S.O.) had previous vocational experience working in the community where several of the participants reported living and therefore felt it necessary to reflect on her initial thoughts and reactions to the data. This also allowed for us to use thick descriptions and participant quotes to justify our interpretations of the data. Taken together, these techniques offered credibility to the data and emphasized the lived experiences of our participants.

Results

Participant quotes have been selected to support the identified themes and to give voice to the participants' experiences. Where square brackets have been used (i.e., [], [...]), wording changes were made by the authors to protect the confidentiality of the participant, or to reflect a selection of a quote taken from a larger participant response. Pseudonyms have been used to ensure participant anonymity. Two themes emerged from the thematic analysis of the survey data: *"I have good times and bad": The importance of external factors* and *Parenting variability: Ongoing learning and an uncertain future*. The first theme "I have good times and bad: The importance of external factors" is delineated into challenges or supports associated with mental health. The second theme "parenting variability: ongoing learning and an uncertain future" reflects the nuanced challenges of parenting a transitional age, autistic youth and the continuous learning process for parents amid an uncertain future for their loved one.

Theme 1: "I Have Good Times and Bad": The Importance of External Factors

Mental health and wellbeing were discussed by all participants with varying degrees of strengths and challenges. Caregivers expressed how their mental health has changed as a result of the COVID-19 pandemic, listed daily strengths and challenges, and reflected on strategies in which they engage to support their own mental health. The prevalent theme among these responses were that external factors can either support or exacerbate parental mental health and wellbeing. These factors included the COVID pandemic, the complexity of their child's needs, financial difficulties, lack of access to resources, coping strategies, and support received from family and friends.

Mental Health Challenges. Stress and self-described anxiety were reflected by several caregivers related to the ongoing nature and uncertainty of the COVID-19 pandemic. When asked about their current stressors, some caregiver responses were: "What if we cannot go back to the old normal" (Lucia); "Fear of not knowing when this pandemic will end" (Erika); and "Uncertainty around virus and employment." (Sanaa). Other caregivers discussed how the complexities of their children's needs, coupled with little caregiving support negatively affected their mental health. Marital relationship difficulties and concerns for family wellbeing were also discussed. For example, Arielle stated:

My husband does not participate in the care of my two boys who both have ASD [autism spectrum disorder]. One has multiple diagnosis, in a wheelchair, g-tube fed and needs full time care (19-year-old). My second son who has ASD and ADHD [attention-deficit/hyperactivity disorder] is currently struggling with COVID school (has failed 2 courses so far this year in grade 12). My husband has no relationship with my second son and they are often at odds with each other. My daughters who were my support at home now both live away from home so I have less support. I feel unappreciated and lonely in this marriage, but do not have the means to leave this marriage. I worry about the future for my 19-year-old (and 16-year-old to be frank). I don't have a plan yet for their care but that needs both my husband and I to

meet with professionals to help us make that plan and it never seems important to him to do that. My mom, my best support, is 86 and I am terrified every day that she won't pick up the phone and be ok... I have gained 10 pounds over COVID :(

Similarly, other parents discussed the impacts of having multiple children, with and without autism and how these dynamics have been challenging. Shanice stated “[having] two very different and complex kids cannot get along. under the same roof. We have had to get creative to separate them”; and Mallory commented “Also stressed of having an 11-year-old on the spectrum, plus two other children. Not enough for them to do outside of the home. We are sick of each other and always fighting.”

Finances were also identified as an important factor that influences caregiver wellbeing. Mohammed discussed the expenses he incurred trying to keep his son engaged, while not having a stable income: “Money (as I have spent over \$7000 in gas driving him around) and with not being able to work since I was looking after him full time, Keeping him somewhat under control.” Whereas Jennifer expressed concern about financial planning for the future and how this could shape their retirement plans:

[...] Also stressing about saving enough for him to retire before I can retire. My hubby is retired but I want him to go back and double dip enough to set my son and us up better. But he was at the end of his rope. Oh and our dog's cancer is back and treatment has been delayed by a week while we isolated. Same with fixing our furnace. I saw a slogan on Facebook - I tried my month free subscription to 2021, I don't want it to continue.

Additionally, caregivers discussed the concerns they have about their own health and that of their family members, particularly in light of the pandemic. For example, some responses were: “I am high risk (autoimmune disease) and my son is high risk (heart failure).” (Shanice); “[...] looking after myself as I have heart problems (I had heart failure a couple of years ago).” (Mohammed); and Karen commented:

Husband without full time employment. Health concerns re: COVID as I consider myself high risk with asthma and a blood clotting disorder. No family in Ontario. Kids coping quite well considering but worries related to our son's (ASD) rigid thinking, poor choices related to health and self-care (e.g. food intake and sleep habits), organization and school focus, does regularly stress us out, me more than my husband.

Supported Mental Health. A variety of factors also contributed to positive wellbeing and mental health including access to resources, coping, support from one's co-parent/co-caregiver, and adequate finances. Co-parenting support was particularly emphasized as being critical for supported mental health, as evidenced by Estrella:

My husband has been amazing supporting me exercising a few times a week during the day when I still have energy. If I left it until the evening, I would totally lack the motivation. I try to eat decently. When I feel all the negative thoughts creeping in, I try to take a step back to look at the bigger picture and focus on the positives. My husband and I make a good team so supporting each other in our struggles and negative times is amazing (not that we always get along or are always on the same page). I do text frequently with friends (both those that have children with autism and those that don't) to keep me feeling connected.

Similarly, Bailey suggested that support from her family has been something that supports her mental health and wellbeing: "Mostly my family, my husband and I support one another. Also, my daughter will help from time to time."

Social support from friends was also cited as an important resource, as some parents reflected that the absence of having time with friends and family was detrimental to their wellbeing (e.g., "I miss walking and talking with my friends" [Jennifer]; "Social distancing is very difficult with family members not in the bubble, not being able to hug" [Tiffany]). Positive examples of social support included: "Surrounded by family friends, continuing to have employment." (Erika); "Having my social contacts to go walking with [...]" (Tiffany); and "Friends and family. Walking especially with friends and family [...]" (Jennifer)

Resources, such as food, fitness, and professional services were also described as important factors that promote caregiver wellbeing. For example, Arielle stated that her resources include: "My therapist, working out (when I can because I have to have a caregiver here to look after my son), my daughters, my mom, wine." Other caregivers discussed walking the dog, and physical activity as beneficial to their wellbeing, while another specifically discussed financial resources and employment as their supports: "Work, making money." (Fallon)

Some parents provided a variety of factors that contributed to their positive wellbeing, suggesting that a multitude of supports can exist and be accessed. Karen, for example, stated that her supports come from: "Calm environment. Sleep and good food. Support spousal relationship. \$ in the bank. Time with our foursome family." While Mallory listed: "Chocolate. Good meals. Sleep." Both Morgan and Jennifer reflected that they enjoy being able to plan things, which is important for their mental health: "Reading, dog walks, training at home, family video night. Planning for special events: Halloween, Christmas rituals." (Morgan); "Reading. Puzzles. Trying to do mindfulness with my own private therapist. Having a plan- I hate anything where I don't have a plan." (Jennifer)

Mental Health During COVID-19. Prior to the pandemic, caregivers reflected great variability in their mental health with some stating that they had good or strong mental health, while others described themselves as being drained, exhausted, or struggling. One parent stated “Things were building before COVID 19. Covid was just the icing on the cake” (Jennifer). For many parents, COVID had a profoundly negative impact on their mental health and wellbeing. For example, Mallory noted the need for an increase in her medications for a pre-existing mental health diagnosis: “Had to increase my medication dosage. Have a stress related rash that won't go away. Have trouble sleeping, always tired.” Others described a feeling of being trapped and even joked about their own mental health fragility:

It is definitely a stretch to put on a happy face some days because I feel we are trapped in this life with no refuge. I can see that my daughter is also bored as there is not enough stimulation for her. If we didn't volunteer we would have gone mad by now. The only saving grace is that we volunteer at [mental health centre] so when the last marble drops we won't have far to walk for help. (Kai)

Some caregivers expressed frustration with the limitations on services being offered for themselves and their transitional aged youth during the pandemic. “Mixed, some opportunities have opened up but a lot of what I was looking forward to has been cut off or limited.” (Charlie); “Good, but I miss going to the gym, yoga class, and the movies.” (Morgan); and

I have had a hard time since COVID hit. He lost school, [developmental services supports] and sports, We spent 4 to 6 hours in the car a day driving to keep him calm. I have taken him to Hospital EMG and have had people call the police a few times as he has turned on me (punching, kicking) My mental health was not good for a few months but has been a little better since school has started. (Mohammed)

One caregiver shared how isolated she feels and how individuals outside of the autism community do not understand what it is like, yet how she also struggles to maintain connections with friends in the autism community. Estrella disclosed:

I definitely feel isolated, like people outside the autism community have no idea what it's like for us. I have more difficulty making the effort to connect with friends, even good friends, especially in my autism community. The main challenge is that I am too busy homeschooling during the day then too tired or focused on my own family in the evening. I will be honest though, the children of all of my friends in the autism community have returned to school and that's hard for me, feeling like we've been left behind almost. I have good times and bad, trying to exercise, eat decently, focus on the

positives etc; take care of myself so I can keep our son moving forward. It takes a lot of resilience some days. I am not looking forward to the depths of winter. I am doing ok. I worry about my husband trying to work from home. He can be a worrier and is concerned about both our son and me.

Mental health presentations varied greatly between parents of transitional aged, autistic youth. Heightened anxiety and depressive symptoms were reported by many parents during COVID-19, while frustrations and other mental health challenges were exacerbated by external factors such as lack of support, and resources, as well as having more than one child with complex needs. Positive mental health and wellbeing were also influenced by external factors including adequate resources, supports, and finances. Notably, there was overlap between parental mental health and parenting and co-parenting relationships.

Theme 2: Parenting Variability: Ongoing Learning and an Uncertain Future

The second theme encapsulates the diverse parenting experiences and meanings expressed by caregivers. While each had their own unique parenting experience, almost all caregivers described their parenting as challenging. Many reflected that parenting a transitional aged youth with autism is a continuous learning experience and that learning continues to shift in an effort to prepare for the unknown of their child's adult life. Parents were able to reflect on the strengths of their parent-child relationship and many of them discussed unconditional love, their child's kindness and sense of caring, their child's accomplishments, and the time that they spend with their child. When describing their overall experience and meaning associated with parenting, the struggles and difficulties were particularly emphasized.

Challenges of Parenting. Parenting challenges were reflective of myriad factors including the complexities of their child's needs, as well systemic barriers that are preventing their child from accessing services. Bailey described the challenges of parenting, navigating systems and the emotional journey of parenting a transitional aged youth on the autism spectrum:

It has really been the most challenging thing of my life, continues to be. Navigating the system to find help, the waiting lists, I even took a lot of these courses myself while waiting for IBI treatments, the costs that you pay. This has been a full-on journey since his diagnosis when he was almost 3. Having an older child worrying about her well-being and attention. We have been through a lot mainly because of our son's disability and obviously continue on that journey. We are trying to balance our own lives but try to make sure he is having a great one too. Sometimes this is so heartbreaking and you feel guilty that it's possible that you are still not doing enough.

The reflection of guilt and concern about not doing enough was noted but other caregivers as well. As Arielle explained, challenges supporting a transitional age, autistic youth continue as she too ages, and that this experience is incredibly complex:

[...] In the past year he has grown to be bigger than me and my husband. The physical challenges of looking after him are growing as I age. He still has interests of a toddler. My house doesn't get to grow up...we have 24 Elmos, cause and effect toys, picture books. His interests are limited and he needs someone interacting with him most of the time. He cannot be left alone. When he is at home he is my responsibility. I cannot leave him with my husband because he has not learned enough to keep him safe. He wears a helmet for his seizures and once I left him with my husband to use the washroom and my son had a seizure, fell and we were at the hospital with a concussion... He is usually happy, but when upset can become physical - hitting, pinching, pushing and now because he is bigger it hurts. I worry - all the time. Is he safe? (when at school, out with a worker, if I let go of his gait belt will he have a seizure?) Am I doing enough? What will happen when I am gone? My experience is lonely, scary and loving too. On the flip side, we celebrate any new skills like crazy! He is funny and sweet and loves people and loves me deeply as I do him.

Other caregivers, such as Shanice discussed the challenges with having children with complex needs, without adequate professional involvement and validation:

Autism diagnosis came very late (age 21) despite years of advocating. Professionals always brushed it off as being mental health. Very hard to find helpful supports for a complex individual (both my kids are highly complex). There is no help for them. Very difficult to parent in a family where everyone is so different, so needy and so dependent.

The systemic barriers and difficulties with service providers was echoed by Morgan, though they expressed tentative fears about a resurfacing of prior behavioural concerns:

At times it has been very difficult. Finding the proper medical and social supports for his behavioral issues has been frustrating and expensive. We have had several police visits for some of his outbursts. Getting him medicated properly for his anxiety and mental health issues was very challenging. Just finding a doctor who was willing to work with us who had the expertise was difficult to do and expensive and then the initial drug treatment caused him to hallucinate to such a disturbing degree that we had

to take him to the hospital for observation. The last few years have been quite a bit better, but we are always wary and watching for signs of past behaviors which indicated things were not well.

Ongoing Learning. For parents of transitional aged, autistic youth, learning was described as a continuous process. This learning incorporates an understanding of the self as a parent, the child and their presenting concerns, which may change over time, and how to navigate the system. One caregiver used an analogy to describe her parenting experience reflecting a process of perpetual education. This comment not only reflects the complexity of the learning, but also its enduring nature:

How much time do you have. It is like taking a lifelong University course. There are always challenges and so much to learn. Most parents don't have to deal with all that parents with a special needs child/adult do. For instance, food allergies/sensitivities, anxiety, OCD (obsessive-compulsive disorder), speech issues, sensitivity to large crowds and noise, etc. (Kai)

Other caregivers actively sought to expand their knowledge about their child's diagnosis, which was helpful for them to understand their own needs and empathize with their son, ultimately strengthening their relationship:

When he was first diagnosed, and I did some research, figured out I and the male members of my family probably had Asperger's. That opened my eyes and explained a lot of things. Knowing that gave me an understanding of myself and what I had to work on (social skills, shyness, change from regular routine, hating noise) and also helped me understand what my son was going through. I have been raising him since he was about 13 so we have a very strong bond. Also, as I get older and start losing my memory, (I have explained to him about dementia and Alzheimer's) he is part of team with me, we look after each other. (Charlie)

Parents also discussed learning by comparison to others. For some (e.g., Kai) it was comparing their experience to other parents "A huge learning experience and a source of pride. I am happy so far with the results but like most parents I wish I could do more for my daughter.", while for others, comparisons were made to their other children, and to neurotypical peers:

Can be isolating and complicated! Can also be fun treating him in a more adult way. There are limited programs that welcome youths on the more severe end of the spec-

trum. It becomes more complicated to sort through the root of behaviour when you add hormones and a changing body into the mix. We were lucky to have the experience of parenting our older children but still have to remind ourselves that we need to grow along with him. His interests change, he can be moody, his body changes, just like a neurotypical teen. (Estrella)

Concerns for the Future. Many caregivers expressed fears about their child's future, due to a lack of support, preparation, and uncertainty about whether or not their child will thrive. For example, parents said: "Very challenging and stressful, scared for his future to survive himself" (Lucia); "There are many concerns for his future and not much out there to support him, or us." (Mallory); "[...] But once he turned 18 it's like the government thinks they're magically cured [...]" (Afrah); and "Trying to get him to prepare for his future continues to be difficult. [...]" (Tiffany).

Disillusionment was also reflected in Jennifer's statement regarding their child's level of independence, and the 'cracks' that exist in the system:

[...] And when you sign up to be a parent you think they will leave home by 30 anyway. I have no idea how he will be able to work or live alone. But he's not considered low enough functioning to get DSO² He does get ODSP³. But who can live on that. I was part of [public consultation and advocacy efforts] for people with ASD. Glad I could be part of it because no one represents kids like my son who fall through the cracks. Not low enough functioning to get a lot of the help but not able to be fully independent [...].

This uncertainty around the future reportedly contributes to heightened parental anxiety, as explained by Karen:

[...] I have high anxiety because of worries about the future. Will he establish strategies and habits by adulthood that will support his decision making once he's 18? Can we support him finding a healthy focus to study towards a career? Can we keep him away from marijuana to 21 (having already been down that road a bit...)? Will he ever want to choose the actions that support his own health and success without our daily support (even with self-care.)

Relational and Situational Factors Affecting the Parenting Relationship. COVID-19, among other factors, was something noted to affect the parent-child relationship, particularly due

² Developmental Services Ontario: Adult developmental service entity in the Province of Ontario

³ Ontario Disability Support Program: Income and/or employment support program

to the increased time spent together at home. As Estrella described “SOOO much time together with me homeschooling - what teen wants that? I must really annoy him sometimes and he can get under my skin at times as well!”. Other challenges include having other children with complex needs and not having sufficient co-caregiving support. Both of these factors were identified by Erika who stated: “Very challenging to manage a youth with autism, adding to that being a single parent with another teenager going through mental health issues.” Parenting and raising a transitional aged, autistic youth reflects complex relational dynamics, described by many parents as challenging. A multitude of factors contribute to these challenges, including systemic barriers, lack of supports, having family members with differing support needs and the pressure on many parents to plan for their child’s future. Continual learning and personal growth were described by parents during their child’s transitional age of development, with several participants reflecting on parenting differences with their other children.

Discussion

With growing consensus that no two children on the autism spectrum are exactly alike, it stands to reason that the experiences of parenting autistic children are also diverse. The present study revealed an absence of a monolithic experience of parenting a transitional aged, autistic youth; rather, there were diverse experiences influenced by a myriad of factors including the level of co-caregiving supports, the needs of the child, systemic barriers, the parent’s own presenting mental health and wellbeing, and other external elements such as a global pandemic. Although parents were not explicitly asked to rate their overall mental health on a Likert-style scale as conducted in other research (e.g., McLaughlin & Schneider, 2019), written descriptions of their mental health ranged from “very poor and depleting”, to “good/strong”. The impact of COVID-19 also profoundly affected parental mental health and wellbeing due to the increased restrictions on supports/services and increased role demands for the caregivers. As social supports have been identified as a predictive factor of parental wellbeing (Falk et al., 2014; Smith et al., 2012; Teehee et al., 2008), it is not surprising that due to the COVID-19 restrictions at the time of the study and the lack of available supports and resources, parental mental health had been negatively affected, particularly for single parents who rely on outside caregiving supports (e.g., respite/professional organizations). Future research could explore these impacts in greater detail and determine whether the declared ending of the pandemic in May 2023 brought about any changes in parental mental health and wellbeing, though early research suggests that the mental health outcomes for these parents has been tenuous and there will be need to explore interventions and coping strategies in more depth (Brown et al., 2020; Calvano et al., 2021; Corbett et al., 2021).

Parenting relationships were discussed throughout the surveys addressing the perceived meaning and experiences of raising a transitional aged youth with autism. These meanings evidently evolved throughout one’s parenting journey, with some parents reporting that their parenting seemed easier at this stage while others believed that it became more complex. Shifts in parental responsibilities have also been particularly evident throughout COVID-19 due to the caregiving role ambiguity and additional roles that parents took on resulting from service closures, including home schooling, acting as clinicians, and being the organizers and constant companions

for their child(ren). While there is discussion within the literature regarding how role ambiguity is prevalent among parents of autistic children (e.g., Falk et al., 2014; Gentles et al., 2019; Maich & Hall, 2016), the results of the current study suggest that COVID-19 had further exacerbated this demand. Though limited Canadian research explored the impact of COVID-19 and parenting for transitional aged, autistic youth, let alone children with disabilities in general, one UK study reported that parents of children with special education needs felt ill-prepared for the added responsibilities and role expectations that came with homeschooling during the closures of schools (Greenway & Eaton-Thomas, 2020).

Positive and challenging parent-child relationship elements reflected a variety of internal and external factors. Consistent with Carter et al. (2015), positive child characteristics including unconditional love and kindness were appraised as helpful factors within a strong parent-child relationship. Caregivers in this study added that their child's sense of humour, cleverness, and resilience benefitted their relationships, and even were empowering to the parents. Factors that challenged the parent-child relationship included complex behaviours of the child, systemic barriers, and lack of support from co-caregivers. Lack of support has been discussed in the literature particularly in relation to single-parents (e.g., Bromley et al., 2014); however, in the present study, lack of support was more often discussed by married parents, reflecting ongoing tensions within their co-caregiving relationship. Co-parenting relationships, then, appear critical to one's perception on mental health. It should be cautioned, however, that COVID-19 may have influenced this perception due to increased parenting role demands, changes in employment (availability of work, working from home, and/or income), and the overall increase in family tension during the provincial stay-at-home orders. Taken together, external factors such as finances, their child's complex needs, lack of resources, systemic barriers, the pandemic, and lack of support negatively affect their mental health and parenting relationships, while added supports and resources positively affect these constructs. Parents were clear in their responses that lack of supports, be it from their co-parent, and/or service providers, are detrimental to their relationships and overall wellbeing, while the presence of supports, including those from a co-caregiver, partially buffered mental health concerns.

Limitations

The method of using open-ended survey questions, though convenient, was a limitation in this study as the depth of participant responses may not have been as rich in detail as would be in an interview. Lack of diversity among the participants' characteristics and the gender identity of the respondents were also notable limitations. Future research should aim to include more fathers and participants from diverse backgrounds to better understand these underrepresented perspectives. With the disparate nature of the COVID-19 pandemic restrictions, questions related to COVID may have only captured participants' reflections in that particular moment, as opposed to holistically. Language use, including the term "functioning" was another limitation within this study. While several parents used the term "high functioning" when describing their child in this study, it may not be representative of the presentation of their child's needs and abilities. Future research could continue to explore autistic youth and caregivers' preferences around language use,

narrowing in on preferential terms and phrases, rather than only on the broader constructs such as person-first vs. identity-first language and “functioning level.”

Conclusions

This study revealed a complex interaction of internal and external factors influences parental mental health and wellbeing and the relationships they have with their autistic youth. Experiences with mental health and relationships prior to- and during COVID-19 reflected a breadth of strengths and challenges at multiple systemic levels, including the family system and the service system. Though concerns with the service systems pre-dated the pandemic, situating parental experience around the context of COVID-19 provided a unique opportunity that highlighted the additional challenges and exacerbated apprehensions with gaps in the system. Among other identified hopes for change, parents particularly emphasized their need for non-judgmental support in the service system, the family, and in the broader community. The results of this study encourage the demand for changes to these systems, namely, increasing the availability of relevant resources and supports to enhance the mental health and caregiving experiences of parents of transitional aged, autistic youth.

*Appendix***Table 1: Demographic Characteristics of Parents**

Variable		Range	<i>n</i>	Mean/%	SD
Gender	Male		3	15.8%	
	Female		15	83.3%	
Sex at Birth	Male		3	15.8%	
	Female		16	84.2%	
Age		41-60		51.0	5.01
Ethnicity	White		14	73.7%	
	Filipino		1	5.3%	
	Black		2	10.5%	
	South Asian		1	5.3%	
	Other (White, Spanish)		1	5.3%	
Relationship Status	Single		5	26.3%	
	In a Relationship (not married)		1	5.3%	
	Married		11	57.9%	
	Divorced		2	10.5%	
	Some post-secondary		1	5.3%	

Education Level	Post-secondary certificate, diploma, or degree		18	94.7%	
Employment	Employed, Part-time		1	5.3%	
	Employed, Full-time		13	68.4%	
	Unemployed, Looking for work		3	15.8%	
	Unemployed, Unable to work		1	5.3%	
	Retired		1	5.3%	
Annual Household Income (Gross)	\$0 - \$19,999		1	5.3%	
	\$20,000 - \$39,999		2	10.5%	
	\$40,000 - \$59,999		3	15.8%	
	\$60,000 - \$79,999		2	10.5%	
	\$80,000 - \$99,999		3	15.8%	
	\$100,000 or more		8	42.1%	
Region of Ontario	Durham		1	5.3%	
	Guelph/Wellington		2	10.5%	
	Halton		7	36.8%	
	Kitchener/Waterloo		2	10.5%	
	London/Middlesex		1	5.3%	
	Peel		4	21%	

	Toronto		1	5.3%	
	Windsor/Essex		1	5.3%	
Number of Children	1		5	26.3%	
	2		7	36.8%	
	3		4	21.1%	
	4		3	15.8%	

Table 2: Demographic Characteristics of Transitional Age Youth

Variable		Other	Range	<i>n</i>	Mean/%	SD
Gender	Male			1 5	78.9%	
	Female			3	15.8%	
	Other	Non-binary		1	5.3%	
Age			16-23		19.9	2.40
Developmental Services Ontario (DSO) Approval	Yes			1 1	57.9%	
	No			7	36.8%	
	Application in Progress			1	5.3%	

Autism/Autism Spectrum Disorder Diagnosis	Yes			1 9	100%	
Adaptive Functioning ⁴	High			8	42.1%	
	Moderate			6	31.6%	
	Low			3	15.8%	
	Other	1). High functioning, without language or behavioural impairments, intellectually gifted, but severely impaired due to mental health 2). *no additional descriptive details provided by parent		2	10.5%	
Other Diagnosed Disabilities	None			3	15.8%	
	Cognitive			1 0	52.6%	
	Mental Health			5	26.3%	

⁴ We acknowledge that functioning level can be both stigmatizing and misleading and that many people in the ASD community are refraining from using this as a descriptive term. See Alvares et al. (2020).

	Other	1) Down Syndrome	1	5.3%	
			1	5.3%	
		2) Learning Disability	1	5.3%	
			1	5.3%	
		3) ADHD			
		4) Brain Injury			
Services Accessed Pre-COVID	None		3	15.8%	
	High School		8	42%	
	Special Education		8	42%	
	Post-Secondary Education		1	5.3%	
	Behavioural Supports		6	32%	
	Communication Supports		3	15.8%	
	Social Supports		8	42%	
	Other	1) Sports	1	5.3%	
	2) Gender Support Group	1	5.3%		
		1	5.3%		
	3) Work Placement	1	5.3%		
		1	5.3%		
	4) Private School				
	5) Individual				

		1 Educatio n Plan (IEP) Supports				
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