

Research Article Resilience among Parents and Children with Autism Spectrum Disorder

Parisa Ghanouni 🕞 and Laura Eves

Department of Occupational Therapy, Dalhousie University, Halifax, Canada

Correspondence should be addressed to Parisa Ghanouni; parisa.ghanouni@alumni.ubc.ca

Received 24 October 2022; Revised 30 December 2022; Accepted 2 January 2023; Published 10 January 2023

Academic Editor: Lut Tamam

Copyright © 2023 Parisa Ghanouni and Laura Eves. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Resilience plays a pivotal role to offset stress among families of children with autism spectrum disorder (ASD). Although the majority of previous studies investigated resilience in parents, it is unclear what factors contribute to resilience in children. Thus, we aimed to explore resilience experienced by parents of children with ASD and how it affects children's resilience. We invited 50 parents of a child with ASD, 13 years old or younger, across various Canadian provinces in an online survey. Parental resilience was positively associated with household income and negatively associated with parental stress. Resilience in children with ASD was positively associated with their social participation at home and community. Findings indicate a relationship between resilience in children with ASD and their participation, suggesting new ways to increase resilience in children with ASD by enhancing their participation.

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder affecting 1 out of 59 children [1]. This disorder is identified by early demonstration of social communication deficits in addition to repetitive and restrictive behaviours and interests [2]. Given the long-term need for behavioural interventions and rehabilitation services for individuals with ASD, parents and caregivers of children with ASD usually face an economic and personal burden in providing resources for their child.

For parents, it is often difficult to predict their child's behaviour due to the unique expression of the disorder and communication patterns [3]. As a result, parents raising children with ASD experience significant levels of stress that may impact family functioning [4]. Social support such as family emotional support can help reduce parental stress [3]. Financial support is another important consideration for parents as children with ASD require more support in the form of therapeutic services and caregiving than neurotypically developing children [5]. Given the life-long nature of ASD, parents of children with ASD experience high levels of stress and anxiety [4]. The ability to be resilient, that is persevering successfully through adversity, enables parents to maintain a functioning family, reduce stress levels, and better support the child [6].

Resilience is often defined as a dynamic process encompassing positive adaptation within the environment. Resilience can include the cumulative effect of personal attitudes, beliefs, and skills, enabling individuals to be successful in the face of adversity [7, 8]. According to the theoretical framework about resilience, individuals' resilience is determined based on how well they can balance both risk and protective factors [8, 9]. Several models including ABC-X model or double ABC-X model can provide frameworks to identify factors that determine the relationship between stressful events and crises in families. The stressor event (A), the resources available (B), the family's perceptions of the stressor (C), and the likelihood of crisis (X) can help analyze stress and coping within families [10]. The resiliency model of family stress, adjustment, and adaptation describes a family's ability to adapt to their adverse situation based on their resources including the family, social and community support, and coping abilities [11]. In a collaborative model of resilience, the contribution of systems in the community, family, and other groups assists in developing resilience among individuals and can help support their wellbeing [12–14].

Resilient parents are receptive to the ongoing needs of the child with the disability [15]. However, several risk factors including symptom severity or difficulty level, the number of children with ASD, financial difficulty, and marital quality may contribute to the parental stress and their resilience [16]. Behaviours supporting resilience were often observed to be related with family cohesion, parental acceptance, dyadic parent unity, and parental positive engagement [17, 18]. It has been shown that self-reported parental stress can be mediated by perceived level of resilience [16, 19]. Parents who see themselves as able to cope with parenting challenges report lower stress levels [20, 21].

Resilience is not only critical for parents of children with disabilities, but for children with ASD to be able to navigate and thrive in an ableist world. Having a developmental disability such as ASD decreases social participation and may lead to negative life outcomes [22]. Furthermore, children with ASD are more likely to experience peer exclusion and bullying, which may result in reduced social activities. Both the number of friends and ability to sustain friendships are usually reduced in children with autism, further limiting social engagement [23]. Combined with the intrinsic challenges of living with a disability, living in an unstable and stressful environment may only exacerbate those challenges. As parents become more resilient, empowering their children with ASD to persevere through adversity, may result in stronger resilience skills for the child.

Although previous literature has explored resilience in parents, there is very limited information about resilience in children with ASD. As parents develop skills to increase resilience and improve family functioning, resilience in the child with ASD might develop concurrently. The objective of this study was to explore stress and resilience experienced by both parents of children with ASD and their children. We were interested in identifying factors that may promote resilience in children and parents and what, if any, connection exists between a parent's level of resilience and their child's level of resilience. Given the effects of social participation on emotional wellbeing, we hypothesized that social participation in children with ASD is positively associated with children's resilience. Furthermore, we hypothesized that parental stress level can negatively affect their resilience.

2. Methods

2.1. Participants. The project is aimed at recruiting parents/ caregivers of children with ASD 13 years old or younger. The age range was selected because at this point, most families have received children's healthcare services. Focusing on adolescents and adulthood was beyond the scope of this study. Families needed to have their children officially diagnosed with ASD by a psychologist using ADOS or ADI-R. Families must have previously or currently been receiving services at the time the survey was completed. All participants must have been able to complete the survey in English. To be able to recruit a diverse sample, we did not set any specific criteria regarding the extent of the difficulty/severity of the disorder and comorbidities. Exclusion criteria included parents of children with ASD who at the time of the survey were older than 13 years old. Parents with children receiving services outside of Canada were not included. Parents with more than one child receiving services were permitted to fill out a second survey. In this case, we provided a condensed version of the first survey as to avoid needing to repeat demographic information about the parent and family dynamics.

We recruited 50 parents (98% females), ranging in age from 26 to 65 years (mean = 38.66 and SD = 7.59). Majority of them (N = 42) had a boy with ASD and the rest (N = 8)reported to have a female with ASD. The average age of children was 7.52 years (SD = 2.71), ranging from 2 to 11 years. Participants are self-identified as Caucasian (90%) and Asian (10%). Marital status of parent participants varied ranging from married (76%), common law (10%), divorced (6%), single (6%), and engaged (2%). Participants were residents of seven Canadian provinces including Alberta (6%), British Columbia (36%), New Brunswick (6%), Newfoundland and Labrador (10%), Nova Scotia (26%), Ontario (14%), and Prince Edward Island (2%). The total number of children in each family regardless of ASD was reported as the following: one child (24%), two children (58%), and three children (18%). Parents also reported the number of children in their household with any type of disability. Having one child with disability represented 72%, two children with disabilities represented 26%, and three children with disabilities represented 2% of the participants. The most common services received by children with ASD were diverse and multifaceted, included speech-language pathology (42%), occupational therapy (40%), and applied behaviour analysis (30%).

2.2. Recruitment. An email detailing the purpose of the study and aims was disseminated to our target population. Using convenience sampling, we distributed posters and invitation letters among clinics, organisations supporting individuals with ASD, and community centres across Canada via email. We also considered snowball sampling by asking those who expressed interest in participation to pass on the information among their networks. Given our sample size of 50 parents and heterogeneity among our participants, we think that the sample can be a good representation of the population. Electronic consent was obtained through the survey platform. The first page of the survey required participants to check a box to indicate their consent in participating in the study.

This project was approved by University Behavioural Research Ethics Board.

2.3. Survey Questions. Our survey was comprised of multiple standardized questionnaires with established psychometric properties, including validity and reliability. The questions were aimed at measuring parental stress level, their child's difficulty, children's levels of resilience, parental self-reports of resilience, and demographic information.

The Parental Stress Scale (PSS) is a 5-point Likert scale that asks parents to rate their agreeability to 18 statements regarding their positive and negative experiences of parenthood. A lower score indicates a lower level of parental stress [24–26]. This scale has been widely used in the literature with a good internal consistency, good constructor validity, and a good reliability [25, 26].

To collect children's difficulty level as an index for severity of the disorder, we used Strengths and Difficulties Questionnaire (SDQ). The validity and reliability of this tool have been determined satisfactory, attesting to the feasibility of its use as a screening instrument [27, 28]. This checklist comprised of Likert scale items (not true, somewhat true, and certainly true), asking about the level of difficulties in several areas, and how these difficulties interfere with the child's everyday life (not at all, a little, a medium amount, and a great deal). Child difficulty scores reflect the severity of the associated challenges children with ASD experience. The questions were pulled from the Parent Report Measure for Children and Youth [29]. A higher score on this questionnaire indicates a high risk of clinically significant problems in the area of functioning [27, 28].

The Child and Youth Resilience Measure (CYRM) is a measure of resilience indicators in children as reported by their primary caregiver. This checklist has been shown to be a valid and reliable measure of resilience [30–32]. The survey consists of 26 statements, each with a 3-point Likert scale (no, sometimes, and yes). The CYRM provides information on three domains including: individual (personal skills, peer support, and social skills), contextual (spiritual, education, and cultural), and caregiver (physical care giving and psychological care giving) that relate to children's resilience [31]. A higher score on this measure corresponds to the increased presence of resilience factors in the children's life [31–33].

The Child and Adolescent Scale of Participation (CASP) evaluates the child's participation in different contexts. This parent-report measure has been demonstrated to have a good internal validity and excellent test-retest reliability [34, 35]. We included two sections with a total of 10 subquestions evaluating the child's participation in home and community contexts. Parents were required to respond to a 5-point Likert scale (age expected, somewhat limited, very limited, unable, and not applicable) statements comparing their child to other children of the same age. Lower scores on the CASP indicate decreased level of participation [34–36].

Parenting Resilience Elements Questionnaire (PREQ) was used to measures parent resilience. This tool has been considered as a valid and reliable tool, which is capable of measuring caregiver's level of resilience [37]. The PREQ consists of 16 questions, which ask the parents to rate their agreeability to the statement on a 7-point scale (definitely not true, not true, rather not true, neither, rather true, true, and definitely true). Responses to the questionnaire evaluate several domains of resilience: knowledge of the child's characteristics, perceived social supports, and positive perceptions of parenting [37]. A higher score on this measure is indicative of lower levels of both psychological distress and overreactive parenting [37]. This questionnaire is capable

of measuring caregiver's level of resilience independent of the level of difficulty of the child's behaviour [37].

Together, the aforementioned questionnaires were consolidated and administered using an online link. Participants were also asked to fill out demographic questions regarding their age, sex, ethnicity, number of children with disabilities at home, monthly household income, their children's age, sex, and children's background.

Throughout the course of collection, two reminder emails were sent to participants who had expressed interest in completing the survey. A unique participant identification number was given to each individual who expressed interest in completing the survey. Interested participants were entered into a draw for a 30 gift cards each valued \$50 to thank them for their time.

2.4. Data Analysis. We conducted a descriptive analysis including standard deviation and average for each demographic variable. Data was checked for the normal distribution using the Kolmogorov-Smirnov test. We conducted an independent t-test to identify any differences in the measures between male and female children. To examine the association between variables, we used the Pearson's correlation coefficient. A correlation of .10 was considered to represent a weak or small association; a correlation coefficient of .30 was considered as a moderate correlation; and a correlation coefficient of .50 or larger was considered to represent a strong or large correlation [38, 39]. We also performed two regression analyses to further explore parent's and child's resilience, each one in a model as the selected dependent variables. All analyses were performed using IBM SPSS and the level of significance was set to be below 0.05.

3. Results

To analyze data, we calculated mean and SD of each measure among participants (see Table 1). Using independent t -test, there was not any significant difference of the measures between male and female children.

Pearson's correlation analysis was conducted to investigate the association between children resilience measures, parental resilience, parental stress levels, child difficulty, and parent's and child's age. Parental stress had a negative moderate correlation with measures of child resilience at the level of personal skills, total individual resilience, educational context, and overall resilience measures. Parental stress level was shown to have a negative strong correlation with the parental resilience, perception of parenting, and perceived social support. Furthermore, a moderate positive correlation between parental stress and children's difficulty/ severity (r = 0.36 and p = 0.01) was identified. Although children's level of difficulty was negatively correlated with measures of child resilience, this was not observed with parent resilience. A weak negative correlation was indicated between children difficulty and children's social skills as well as physical caregiving. Moderate correlations were identified with peer support, total individual resilience, psychological caregiving, total caregiving, and cultural context. Strong associations were indicated between children

TABLE 1: Descriptive measures separated by children's sex.

	Male $(N = 42)$	Female $(N = 8)$
	Mean (SD)	Mean (SD)
Participation		
Home	68.85 (14.05)	74.48 (13.25)
Community	61.88 (14.48)	67.97 (09.70)
Total	66.06 (13.30)	71.88 (11.08)
Child resilience		
Individual		
Peer support	63.25 (22.67)	62.50 (24.80)
Personal skills	73.08 (10.89)	69.79 (15.39)
Social skills	77.78 (16.12)	77.78 (14.54)
Total individual	72.46 (12.10)	70.83 (13.92)
Caregiver		
Physical caregiving	82.91 (08.95)	79.17 (07.71)
Psychological caregiving	88.72 (07.97)	93.33 (05.04)
Total caregiver	87.06 (07.07)	89.29 (04.92)
Context		
Spiritual	51.71 (16.12)	50.00 (15.43)
Educational	70.94 (26.68)	70.83 (21.36)
Cultural	74.64 (15.70)	79.17 (21.77)
Total context	66.38 (14.41)	68.06 (15.64)
Overall resilience	75.45 (09.50)	75.95 (10.78)
Parent resilience		
Child-raising knowledge	30.19 (17.06)	27.14 (24.14)
Perceived social support	35.86 (20.50)	32.94 (22.10)
Perception of parenting	50.65 (23.39)	53.57 (28.72)
Total	25.51 (23.17)	31.49 (18.06)
Parental stress	55.87 (11.03)	58.75 (11.08)
Child difficulty	78.13 (14.73)	72.29 (18.71)

difficulty and personal skills and overall measures of children resilience. Children's age was not significantly correlated with any measure of child or parent resilience. Similarly, parents' age was not significantly correlated with child or parental resilience. No significant relationship between parental stress level and children's age (r = 0.20 and p =0.15) or parent's age (r = 0.25 and p = 0.07) was detected. Similarly, no significant relationship was identified between children difficulty and children's age (r = 0.14 and p = 0.31) or parent's age (r = 0.03 and p = 0.80). See Table 2 for further details.

We examined the correlation between the child's level of participation across three domains (home, community, and total) and measures of resilience. Total child measure of resilience was yielded statistically significant results with moderate strength correlation for community participation and a strong correlation across home participation and total participation.

At the individual category of resilience, the total score of children resilience was positively correlated with participation at home, community, and total, with a moderate strength. There was a moderate positive relationship between

personal skills and participation in home and total context. Strong associations were identified for social skills across home and total contexts, with a moderate association identified across the community context. At the caregiver category of resilience, there was a strong association between total caregiving scores and children participation across home and a moderate association with community contexts. Significant positive correlations of participation were identified across all caregiver's contexts except physical caregiving and children's participation in the community. Moderate correlations were identified for significant measures of physical caregiving, while strong correlations were identified for all measures of psychological caregiving. In the contextual category of resilience, children resilience yielded statistically significant results with a moderate correlation across home, community, and total participation. A weak association was identified for educational context and community participation scores. Cultural context was significantly correlated with participation across all domains. Children difficulty was negatively correlated with levels of participation, with moderate strength. These correlations are illustrated in Table 3.

Regression analysis was conducted by considering parental resilience as the dependent variable and other factors including children's difficulty/severity, children participation, parental stress, children resilience, parent's age, monthly household income, children's age, and number of children with disabilities as independent. Analysis showed that monthly household income significantly predicted parental resilience and parental stress level negatively predicted parental resilience. For children resilience, we considered child resilience as the dependent variable and other factors including children's difficulty/severity, children participation, parental stress, parental resilience, parent's age, monthly household income, children's age, and number of children with disabilities as independent. Regression analysis revealed a significant interaction of children resilience with total participation, parental age, and children's age (see Table 4).

4. Discussion

The current study is one of the studies to investigate resilience in children with ASD and their parents and how it is influenced by intrinsic and extrinsic factors. We specifically examined the interaction between child and parental resilience levels to identify if any significant relationship exists. Although our project is not able to discern causal relations between factors, it provides an insight about how parental and children resilience are affected.

As a novel finding, we found that the level of resilience of children with ASD is positively related to their social participation. Specifically, we identified a positive relationship between individual levels of resilience and participation at home, community, and overall participation. Interestingly, scores of cultural context were also associated with participation. A stronger cultural identity has been identified as a protective factor against physical and relational aggression [40]. Perhaps a shared sense of collectiveness and acceptance allows children to participate more broadly in their lives.

Mental Illness

	Parental stress p values (r)	Parent resilience Total p values (r)	Child difficulty <i>p</i> values (<i>r</i>)	Child age p values (r)	Parent age p values (r)
Child resilience					
Individual					
Peer support	0.07 (0.26)	0.22 (0.18)	0.03* (-0.31)	0.53 (0.92)	0.91 (0.01)
Personal skills	<0.01* (-0.38)	0.14 (0.22)	<0.01* (-0.56)	0.23 (-0.17)	0.87 (-0.02)
Social skills	0.55 (-0.08)	0.20 (0.19)	0.07 (-0.26)	0.55 (0.08)	0.08 (0.25)
Total individual	0.03* (-0.30)	0.09 (0.25)	<0.01* (-0.47)	0.99 (≤0.001)	0.48 (0.10)
Caregiver					
Physical caregiving	0.70 (-0.05)	0.53 (0.09)	0.04* (-0.29)	0.96 (≤-0.001)	0.98 (-0.003)
Psychological caregiving	0.35 (-0.13)	0.52 (0.09)	<0.01* (-0.47)	0.44 (0.11)	0.28 (0.15)
Total caregiver	0.37 (-0.13)	0.45 (0.11)	$p < 0.01^*$ (-0.49)	0.54 (0.09)	0.39 (0.12)
Context					
Spiritual	0.62 (-0.07)	0.77 (0.04)	0.48 (-0.10)	0.48 (0.10)	0.19 (0.19)
Educational	< 0.01* (-0.37)	0.16 (0.21)	0.08 (-0.25)	0.60 (-0.07)	0.88 (-0.02)
Cultural	0.10 (-0.23)	0.30 (0.15)	<0.01* (-0.42)	0.60 (0.07)	0.62 (0.07)
Total context	0.06 (-0.27)	0.26 (0.17)	0.01* (-0.35)	0.68 (0.06)	0.47 (0.10)
Overall resilience	0.03* (-0.30)	0.14 (0.22)	<0.01* (-0.50)	0.76 (0.46)	0.39 (0.12)
Parent resilience					
Child-raising knowledge	0.35 (-0.16)		0.43 (-0.13)	0.08 (-0.30)	0.31 (-0.18)
Perceived social support	< 0.01* (-0.55)		0.97 (0.005)	0.67 (-0.07)	0.57 (-0.09)
Perception of parenting	< 0.01* (-0.47)		0.92 (0.01)	0.56 (-0.09)	0.45 (-0.12)
Total	<0.01* (-0.60)		0.59 (-0.82)	0.20 (-0.19)	0.19 (-0.19)

TABLE 2: The correlation of parents' and children's resilience with other variables.

Note: *significance at p < 0.05.

TABLE 3: Relationship between children's social participation and child resilience and difficulty.

		Participation	
	Home	Community	Total
	p values (r)	p values (r)	p values (r)
Child resilience			
Individual			
Peer support	0.07 (0.26)	0.08 (0.25)	0.05 (0.28)
Personal skills	<0.01* (0.37)	0.06 (0.27)	0.01* (0.36)
Social skills	<0.01* (0.53)	<0.01* (0.42)	<0.01* (0.52)
Total individual	<0.01* (0.49)	<0.01* (0.40)	< 0.01* (0.49)
Caregiver			
Physical caregiving	<0.01* (0.41)	0.45 (0.11)	0.03* (0.31)
Psychological caregiving	<0.01* (0.58)	<0.01* (0.53)	<0.01* (0.60)
Total caregiver	<0.01* (0.62)	<0.01* (0.47)	< 0.01* (0.60)
Context			
Spiritual	0.23 (0.17)	0.11 (0.23)	0.15 (0.21)
Educational	0.10 (0.24)	0.04* (0.29)	0.05 (0.28)
Cultural	<0.01* (0.55)	<0.01* (0.45)	<0.01* (0.55)
Total context	<0.01* (0.45)	<0.01* (0.43)	< 0.01* (0.47)
Overall resilience	<0.01* (0.58)	<0.01* (0.49)	< 0.01* (0.58)
Child difficulty	<0.01* (-0.46)	<0.01* (-0.38)	<0.01* (-0.46)

Note: *significance at p < 0.05.

									Child resi	Child resilience model	lel	
-	В	St. error	β	t	р	95% CI	В	St. error	β	t	р	95% CI
Children difficulty 0.	0.22	0.17	0.22	1.33	0.19	-0.12:0.57	-0.04	0.08	-0.09	-0.55	0.58	-0.22:0.12
Children participation 0.2	0.20	0.29	0.14	0.67	0.50	-0.40:0.80	0.45	0.11	0.63	3.78	0.001^{*}	0.20:0.69
Parental stress -1.	-1.45	0.29	-0.80	-4.93	<0.001*	-2.05: -0.85	-0.34	0.18	-0.38	-1.90	0.06	-0.72:0.25
Child resilience -0.	-0.04	0.38	-0.02	-0.12	06.0	-0.82:0.73	I	I	I	I	I	I
Parental resilience	I	Ι	I	I	Ι		-0.01	0.09	-0.02	-0.12	06.0	-0.19:0.17
Age of parents 0.0	0.00	0.11	-0.01	-0.05	0.95	-0.01:0.009	0.006	0.002	0.48	2.83	0.008^{*}	0.002:0.01
Monthly household income 0.0	0.00	0.12	0.37	2.62	0.01^{*}	0.002:0.07	-1.28	<0.001	-0.004	-0.02	0.97	0.001:0.01
Children age -0.	-0.00	0.01	-0.01	-0.07	0.94	-0.03:0.03	-0.01	0.008	-0.41	-2.08	0.04^{*}	-0.03:0.001
Number of children with disability -0.	-0.01	0.05	-0.04	-0.32	0.74	-0.12:0.09	0.01	0.26	0.08	0.57	0.57	-0.03:0.06

_:
children
is and e
parents
among
n models for resilience among parent
for
models
Regression
4:
TABLE

Mental Illness

Children with ASD are not easily integrated into mainstream programming and usually have challenges in social participation that result in poorer quality friendships and lonliness [41-43]. Compared to children with other developmental diagnoses, those with ASD may experience higher rates of social isolation [44]. Aligned with previous studies [45], our data suggests that higher scores of child's difficulty are related to reduced levels of participation. Participation in social activities encourages individuals to manage their symptoms, enhance self-acceptance, increase self-confidence, and allow for generalizability of social skills [46]. Given that sociability is included as an individual protective mechanism in a protective model of resilience [47], children with ASD who demonstrate resilience are also more engaged in their everyday activities. Our findings are consistent with research that demonstrates environmental resources inclduing caregivers' support can facilitate resilience in children [18]. However, our study extends these findings by demonstrating that increased resilience is associated with participation.

Our findings suggest a negative relationship between child difficulty/severity of disorder and child measures of resilience. Severe ASD symptoms may limit a child's ability to form and maintain the same level of social relationships that allow them to develop resilience. This is in an agreement with previous studies that resilience can be built through maintaining positive relationships as individuals are more likely to approach conflict in a positive mindset [48]. Moreover, children's severity of disorder may be related to the children's level of social anxiety, a common cooccurring condition in children with ASD [49]. Although we did not assess the children's level of anxiety, previous research has identified a negative relationship between resilience levels and anxiety or stress symptoms in typically developing individuals [50]. Thus, severity of symptom, which may include increased levels of stress and anxiety, may hinder children with ASD to cultivate individual resilience.

Parents of children with ASD are faced with additional parenting, financial, and personal challenges compared with parents of neurotypically developing children. As parents develop the tools to be resilient, it is plausible that their children will learn and strengthen their resilience alongside them. It is understood that family cohesion and dyadic parent unity are protective mechanisms for children [18]. However, our data was not able to demonstrate any relationship between a parent's level of resilience and their child's resilience. Perhaps, this data suggests that children develop the resilience skills on their own with the support of parents over time. In a challenge model of resilience, children are able to develop skills that lead to positive outcomes [47]. Specifically, parents may act as a protective factor to buffer their child's exposure to negative experiences. This effect has been studied with respect to stressful peer interactions and the effect of parental relationship in children [51]. Another explanation for this data may be that our data may have been insufficient to identify any relationship between parental and child resilience that warrants further investigations in future studies.

We found that children severity/difficulty was positively related to the levels of parental stress. This finding is consistent with the literature as ASD severity may be a predictor of parental stress [21, 52]. Also, we found that parents with lower stress levels scored higher on measures of overall resilience, perceived social support, and perceptions of parenting. Aligned with the models of resilience, protective factors such as social support and personal attributes like perception of parenting are associated with lower levels of stress [47]. From our data alone, we cannot speculate the direction of parental stress and resilience beyond that it suggests they are inversely related. This relationship may be present due to the negative impacts of stress on one's ability to manage situations to overcome adversity [47]. When experiencing high levels of stress, parents may not be able to respond to challenging parenting situations.

The results of our study suggest that parental stress negatively impacts the resilience of children with ASD. Previous research involving parents with young children displaying behavioural problems indicated that parental stress level was clearly associated with a difficulty in noticing and responding to the child's needs and demands [17, 53]. Just as parental stress and resilience were negatively related, this relationship between parental stress and child resilience may be explained by an increased ability of parents to comfort, support, and engage with their child when they are less stressed. Compared to parents of children with typically developing children and children with other disabilities, parents of children with ASD reported more dissatisfaction with financial stress [54]. Parent's financial stress was related to be the result of stunted career development, perhaps due to the need to stay home and care for the child with ASD [54]. The results from our study cannot unpack how exactly parental stress impacts a child's level of resilience. However, another interpretation of this result may be that parents of more resilient children may experience less parental stress. While our survey did not probe into family dynamics, a decrease in family quality of life and increase in familial stress can affect resilience [17, 54].

We found significant interactions between the age of children or age of parents with children's resilience in our resilience model. As children age, they experience and learn how to use resources to adjust or develop better coping strategies to form resilience [55]. An increased number of adverse experiences can expose an individual to more opportunities to grow and learn [56]. However, the results from our survey were unable to corroborate this finding in parents' resilience. Perhaps age is not the optimal metric to assume exposure to new experiences or the extent of exposure that may lead to the development of resilience. Furthermore, children's severity of disorder was not related to the age of parents or children. This implies that the severity of ASD might be highly variable within the population and likely reflects differences in environment factors [57]. Thus, examining the personal and environmental factors that lead to a child/parent resilience warranting for further investigations.

4.1. Limitations and Future Direction. Although this study adds to the literature by explaining factors that affect resilience among children and parents, it has several limitations when interpreting data. First, the small sample size and ratio

of female/male participants in our sample might affect the results. Such rates among children of participants can be due to the higher prevalence of males with ASD compared with females. Second, we did not collect data about family dynamics such as number of siblings with and without disabilities; mental health status of parents; or spousal relationship dynamics, or culture which would be useful information to further comprehend the results. Further, we could not analyze data related to the types of services children receive and this may have affected our results. Third, although we included an index for autism severity in the study, we did not collect information on the comorbid conditions and ADOS/ADI-R diagnostic scores in children with ASD. The lack of child-reported data in this study should also be considered as another limitation. Fourth, crosssectional nature of this study makes it difficult to draw conclusions in terms of cause-effect relations. Last, because our sample was heterogeneous based on the services children with ASD had attended, there is a possibility that other external factors may play some role in resilience that we could not capture. Future studies are recommended to follow an experimental design approach with larger sample size and include more information about external variables such as family dynamics. Furthermore, it is suggested to further explore the child's emotional and behavioural problems using child-reported data and investigate what support programs can help advance resilience. The analysis of each service, how long the child has been attending, and how it may have impacted the behaviours of the children and the parental reported scores of resilience warrants further investigation.

5. Conclusion

This study revealed the relationship of resilience in children with ASD and participation across home and community contexts. Our study emphasizes the importance of mediating parental stress as it may negatively impact the resilience of their children. Thus, resources to support both parents and children are essential to promoting resilience in children with ASD and their parents. Though we did not find a significant relationship between parental and child resilience, further research may identify factors that support the resilience within the entire family.

Data Availability

All data has been shared in tables.

Additional Points

(i) Given that the previous studies only investigated resilience in parents, this study is one of the first studies to investigate the resilience in both parents and children with ASD.(ii) This study reveals that there is an association of social participation and resilience in children with ASD. (iii) This study adds to the body of research regarding resilience in families of children with ASD and what factors are related to resilience in children and parents.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Acknowledgments

This study is supported by the Dalhousie University Faculty of Health Grant.

References

- [1] American Psychiatric Association, *Diagnostic and statistical manual of mental disorders*, 5th edition5th edition, , 2013.
- [2] K. Yates and A. Le Couteur, "Diagnosing autism/autism spectrum disorders," *Paediatrics and Child Health*, vol. 26, no. 12, pp. 513–518, 2016.
- [3] N. H. Falk, K. Norris, and M. G. Quinn, "The factors predicting stress, anxiety and depression in the parents of children with autism," *Journal of Autism and Developmental Disorders*, vol. 44, no. 12, pp. 3185–3203, 2014.
- [4] S. A. Hayes and S. L. Watson, "The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder," *Journal of Autism and Developmental Disorders*, vol. 43, no. 3, pp. 629–642, 2013.
- [5] T. A. Lavelle, M. C. Weinstein, J. P. Newhouse, K. Munir, K. A. Kuhlthau, and L. A. Prosser, "Economic burden of childhood autism spectrum disorders," *Pediatrics*, vol. 133, no. 3, pp. e520–e529, 2014.
- [6] D. McConnell and A. Savage, "Stress and resilience among families caring for children with intellectual disability: expanding the research agenda," *Current Developmental Disorders Reports*, vol. 2, no. 2, pp. 100–109, 2015.
- [7] D. S. Becvar, Handbook of Family Resilience, Springer, 2013.
- [8] S. Stuntzner and M. T. Hartley, Resilience, coping & disability: the development of a resilience intervention, VISTAS Online, 2014, https://www.counseling.org/docs/default-source/vistas/ article_44.pdf?sfvrsn=8.
- [9] S. Luthar, D. Cicchetti, and B. Becker, "The construct of resilience: a critical evaluation and guidelines for future work," *Child Development*, vol. 71, no. 3, pp. 543–562, 2000.
- [10] M. Rosino, "ABC-X model of family stress and coping," *Ency-clopedia of Family Studies.*, pp. 1–6, 2016.
- [11] M. A. McCubbin and H. I. McCubbin, "Resiliency in families: a conceptual model of family adjustment and adaptation in response to stress and crises," in *Family Assessment: Resiliency, Coping and Adaptation: Inventories for Research and Practice,* M. A. McCubbin, A. I. Thompson, and M. A. McCubbin, Eds., pp. 1–64, University of Wisconsin-Madison, Madison, WI, 1996.
- [12] E. Gardiner, L. Mâsse, and G. Iarocci, "A psychometric study of the family resilience assessment scale among families of children with autism spectrum disorder," *Health and Quality* of Life Outcomes, vol. 17, no. 1, p. 45, 2019.
- [13] H. Herrman, D. E. Stewart, N. Diaz-Granados, E. L. Berger, B. Jackson, and T. Yuen, "What is resilience?," *Canadian Journal of Psychiatry*, vol. 56, no. 5, pp. 258–265, 2011.
- [14] L. Kapp and O. Brown, "Resilience in families adapting to autism spectrum disorder," *Journal of Psychology in Africa*, vol. 21, no. 3, pp. 459–463, 2011.

- [15] A. Farrell and G. Krahn, "Family life goes on: disability in contemporary families," *Family Relations*, vol. 63, no. 1, pp. 1–6, 2014.
- [16] A. K. Bekhet, N. L. Johnson, and J. A. Zauszniewski, "Resilience in family members of persons with autism spectrum disorder: a review of the literature," *Issues in Mental Health Nursing*, vol. 33, no. 10, pp. 650–656, 2012.
- [17] L. Hynes, S. Saetes, B. McGuire, and L. Caes, "Child and family adaptation to juvenile idiopathic arthritis-a systematic review of the role of resilience resources and mechanisms," *Frontiers in Psychology*, vol. 10, p. 2445, 2019.
- [18] S. Isokääntä, K. Koivula, K. Honkalampi, and H. Kokki, "Resilience in children and their parents enduring pediatric medical traumatic stress," *Pediatric Anesthesia*, vol. 29, no. 3, pp. 218– 225, 2019.
- [19] P. Ghanouni and G. Hood, "Stress, coping, and resiliency among families of individuals with autism: a systematic review," *Review Journal of Autism and Developmental Disorder*, vol. 8, no. 3, pp. 389–402, 2021.
- [20] V. Bitsika, C. Sharpley, and R. Bell, "The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder," *Journal of Developmental and Physical Disabilities*, vol. 25, no. 5, pp. 533–543, 2013.
- [21] G. Pastor-Cerezuela, M. I. Fernández-Andrés, R. Tárraga-Mínguez, and J. M. Navarro-Peña, "Parental stress and ASD," *Focus on Autism and Other Developmental Disabilities*, vol. 31, no. 4, pp. 300–311, 2016.
- [22] A. Hart, B. Heaver, E. Brunnberg et al., "Resilience-building with disabled children and young people: a review and critique of the academic evidence base," *International Journal of Child*, *Youth and Family Studies*, vol. 5, no. 3, pp. 394–422, 2014.
- [23] F. Knott, A. W. Dunlop, and T. Mackay, "Living with ASD," *Autism*, vol. 10, no. 6, pp. 609–617, 2006.
- [24] R. R. Abidin, Parenting Stress Index, Fourth Edition (PSI-4), Psychological Assessment Resources, 2012.
- [25] J. D. Berry and W. H. Jones, "The parental stress scale: initial psychometric evidence," *Journal of Social and Personal Relationships*, vol. 12, no. 3, pp. 463–472, 1995.
- [26] J. J. Zelman and M. A. Ferro, "The parental stress scale: psychometric properties in families of children with chronic health conditions," *Family Relations*, vol. 67, no. 2, pp. 240– 252, 2018.
- [27] C. R. Hill and J. N. Hughes, "An examination of the convergent and discriminant validity of the strengths and difficulties questionnaire," *Social Psychology Quarterly*, vol. 22, no. 3, pp. 380– 406, 2007.
- [28] C. L. Mieloo, F. Bevaart, M. C. Donker, F. V. van Oort, H. Raat, and W. Jansen, "Validation of the SDQ in a multi-ethnic population of young children," *European Journal of Public Health*, vol. 24, no. 1, pp. 26–32, 2014.
- [29] R. Goodman, "Strengths and difficulties questionnaire [measurement instrument]," 2002, https://sdqinfo.org/.
- [30] P. Jefferies, L. McGarrigle, and M. Ungar, "The CYRM-R: a Rasch-validated revision of the child and youth resilience measure," *Journal of Evidence-Based Social Work*, vol. 16, no. 1, pp. 1–23, 2018.
- [31] L. Liebenberg, M. Ungar, and F. V. Vijver, "Validation of the child and youth resilience measure-28 (CYRM-28) among Canadian youth," *Research on Social Work Practice*, vol. 22, no. 2, pp. 219–226, 2012.

- [32] J. Sanders, R. Munford, T. Thimasarn-Anwar, and L. Liebenberg, "Validation of the child and youth resilience measure (CYRM-28) on a sample of at-risk New Zealand youth," *Research on Social Work Practice*, vol. 27, no. 7, pp. 827–840, 2017.
- [33] M. Ungar, The Child and Youth Resilience Measure (CYRM) Child Version, Resilience Research Centre, 2016.
- [34] F. De Bock, C. Bosle, C. Graef, J. Oepen, H. Philippi, and M. Urschitz, "Measuring social participation in children with chronic health conditions: validation and reference values of the child and adolescent scale of participation (CASP) in the German context," *BMC Pediatrics*, vol. 19, no. 1, p. 125, 2019.
- [35] L. Rainey, R. van Nispen, C. van der Zee, and G. van Rens, "Measurement properties of questionnaires assessing participation in children and adolescents with a disability: a systematic review," *Quality of Life Research: an International Journal* of Quality of Life Aspects of Treatment, Care and Rehabilitation, vol. 23, no. 10, pp. 2793–2808, 2014.
- [36] G. Bedell, "The child and adolescent scale of participation (CASP): administration and scoring guidelines," 2011, https://sites.tufts.edu/garybedell/files/2012/07/CASP-Administration-Scoring-Guidelines-8-19-11.pdf.
- [37] K. Suzuki, T. Kobayashi, K. Moriyama et al., "Development and evaluation of a parenting resilience elements questionnaire (PREQ) measuring resiliency in rearing children with developmental disorders," *PLoS One*, vol. 10, no. 12, article e0143946, 2015.
- [38] J. Cohen, *Statistical Power Analysis for the Behavioral Sciences*, Lawrence Erlbaum Associates, 2nd edition, 1988.
- [39] J. Cohen, "Statistical power analysis," *Current Directions in Psychological Science*, vol. 1, no. 3, pp. 98–101, 1992.
- [40] T. Flanagan, G. Iarocci, A. D'Arrisso et al., "Reduced ratings of physical and relational aggression for youths with a strong cultural identity: evidence from the Naskapi people," *Journal of Adolescent Health*, vol. 49, no. 2, pp. 155–159, 2011.
- [41] P. Ghanouni, T. Jarus, J. G. Zwicker, J. Lucyshyn, S. Chauhan, and C. Moir, "Perceived barriers and existing challenges in participation of children with autism spectrum disorders: "he did not understand and no one else seemed to understand him"," *Journal of Autism and Developmental Disorders*, vol. 49, no. 8, pp. 3136–3145, 2019.
- [42] A. B. Kelly, M. S. Garnett, T. Attwood, and C. Peterson, "Autism spectrum symptomatology in children: the impact of family and peer relationships," *Journal of Abnormal Child Psychology*, vol. 36, no. 7, pp. 1069–1081, 2008.
- [43] R. McConkey, A. Mullan, and J. Addis, "Promoting the social inclusion of children with autism spectrum disorders in community groups," *Early Child Development and Care*, vol. 182, no. 7, pp. 827–835, 2012.
- [44] G. I. Orsmond, P. T. Shattuck, B. P. Cooper, P. R. Sterzing, and K. A. Anderson, "Social participation among young adults with an autism spectrum disorder," *Journal of Autism* and Developmental Disorders, vol. 43, no. 11, pp. 2710– 2719, 2013.
- [45] A. Louwerse, M. L. J. M. Eussen, J. Van Der Ende et al., "ASD symptom severity in adolescence of individuals diagnosed with PDD-NOS in childhood: stability and the relation with psychiatric comorbidity and societal participation," *Journal of Autism and Developmental Disorders*, vol. 45, no. 12, pp. 3908–3918, 2015.

- [46] A. Taheri, A. Perry, and P. Minnes, "Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers," *Journal of Intellectual Disability Research*, vol. 60, no. 5, pp. 435–443, 2016.
- [47] J. Fleming and R. Ledogar, "Resilience, an evolving concept: a review of literature relevant to aboriginal research," *Pimatisi-win*, vol. 6, no. 2, pp. 7–23, 2008.
- [48] T. D. Afifi, A. F. Merrill, and S. Davis, "The theory of resilience and relational load," *Personal Relationships*, vol. 23, no. 4, pp. 663–683, 2016.
- [49] S. White, D. Oswald, T. Ollendick, and L. Scahill, "Anxiety in children and adolescents with autism spectrum disorders," *Clinical Psychology Review*, vol. 29, no. 3, pp. 216–229, 2009.
- [50] O. Hjemdal, P. Vogel, S. Solem, K. Hagen, and T. Stiles, "The relationship between resilience and levels of anxiety, depression, and obsessive-compulsive symptoms in adolescents," *Clinical Psychology & Psychotherapy*, vol. 18, no. 4, pp. 314– 321, 2011.
- [51] N. A. Hazel, C. W. Oppenheimer, J. R. Technow, J. F. Young, and B. L. Hankin, "Parent relationship quality buffers against the effect of peer stressors on depressive symptoms from middle childhood to adolescence," *Developmental Psychology*, vol. 50, no. 8, pp. 2115–2123, 2014.
- [52] A. M. Lyons, S. C. Leon, C. E. Roecker Phelps, and A. M. Dunleavy, "The impact of child symptom severity on stress among parents of children with ASD: the moderating role of coping styles," *Journal of Child and Family Studies*, vol. 19, no. 4, pp. 516–524, 2010.
- [53] M. Östberg, "Parental stress, psychosocial problems and responsiveness in help-seeking parents with small (2–45 months old) children," *Acta Paediatrica*, vol. 87, no. 1, pp. 69–76, 1998.
- [54] R. I. Brown, C. J. MacAdam, M. Wang, and G. Iarocci, "Family quality of life when there is a child with a developmental disability," *Journal of Policy and Practice in Intellectual Disabilities*, vol. 3, no. 4, pp. 238–245, 2006.
- [55] A. S. Masten and A. J. Barnes, "Resilience in children: developmental perspectives," *Children*, vol. 5, no. 7, p. 98, 2018.
- [56] M. Seery, E. Holman, and R. Silver, "Whatever does not kill us: cumulative lifetime adversity, vulnerability, and resilience," *Journal of Personality and Social Psychology*, vol. 99, no. 6, pp. 1025–1041, 2010.
- [57] R. Wozniak, N. Leezenbaum, J. Northrup, K. West, and J. Iverson, "The development of autism spectrum disorders: variability and causal complexity," *Cognitive Science*, vol. 8, no. 1-2, 2017.