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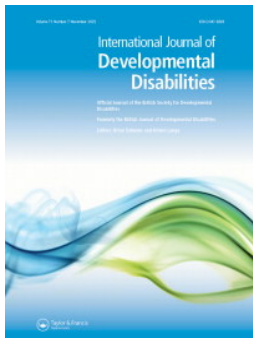
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ABSTRACT

Parents of autistic children face unique challenges, further intensified by the COVID-19 pandemic. This context offers valuable insights into how parents adapt during crises. In this mixed-method study, parenting stress among parents of autistic children (ages 5-22) was longitudinally assessed using the Parenting Stress Questionnaire during a strict lockdown (T1, $n = 49$) and a period with relaxed COVID-19 safety measures (T2, $n = 39$) in The Netherlands. Additionally, deductive thematic analysis was applied to semi-structured parent interviews during T1 ($n = 25$). Results from T1 indicated severe parental role restrictions and mild issues in parent-child relationship, physical health, and overall burden, with normal parenting problems and depressive mood. Parent-child relationship problems significantly decreased from T1 to T2, suggesting improved relationships as COVID-19 restrictions eased and families adapted. Interviews highlighted parents' adeptness at creatively managing pre-existing challenges during the pandemic. However, parents expressed vulnerability and a precarious balance regarding mental and physical health. Using the stress process model, this study shows that parents of autistic children may exhibit greater proficiency in handling primary stressors (parenting and parent-child relationship issues), compared to secondary stressors (role restrictions, depression, and health concerns). These insights offer valuable implications for parenting in times of crises, such as the COVID-19 pandemic.

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Introduction

The COVID-19 pandemic introduced unexpected disruptions to daily life worldwide. In The Netherlands, measures such as physical distancing and school closures, vital for public health, inadvertently enhanced stress and emotional strain for parents (RIVM, 2022). Parents of autistic children, who generally report greater levels of stress compared to parents of non-autistic children (Hayes and Watson 2013; Pastor-Cerezuela et al. 2021), reported increased levels of stress and a desire for more support during the pandemic (Yılmaz, Azak,

and Şahin 2021). As an understanding of the virus and its transmission evolved, the pandemic's safety measures in The Netherlands were adjusted (RIVM, 2022). As such, professionals grappled with the complex task of supporting families, while navigating the fluid landscape of policy changes (Banks et al. 2020; De Jonge, Kloppenburg, and Hendriks 2020). Understanding the evolution of parenting stress and the longitudinal impact of stressors experienced by parents of autistic children, such as during the COVID-19 pandemic, through mixed-method analyses is crucial for tailoring support

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services and shaping future policies that support parents (McCafferty and McCutcheon 2021).

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by challenges in social communication and social-emotional reciprocity, sensitivity to sensory stimuli, and engagement in restricted and repetitive behaviors (APA 2022). Autistic children often benefit from more structured routines and additional supports, including therapeutic services and personalized assistance in educational settings, compared to their non-autistic peers (Dhiman et al. 2020; Hayes and Watson 2013), most of which were disrupted by societal changes imposed by pandemic safety measures (Ameis et al. 2020). Abrupt changes to remote learning and therapy sessions forced parents to assume additional responsibilities as educators, therapists, and social supporters, increasing stress and strain on both autistic children and their families (Amirova, CohenMiller, and Sandygulova 2022; Dhiman et al. 2020; Mazzoni et al. 2022). Meanwhile, external supports were disrupted due to restricted physical proximity, the digitalization of care, and the use of protective gear (Banks et al. 2020; De Jonge, Kloppenburg, and Hendriks 2020). The cessation of support services and community resources, along with the halt of in-person therapeutic interventions, left many families struggling to access essential support networks (Neece, McIntyre, and Fenning 2020). Additionally, parenting stress not only influences parental wellbeing, but overall family functioning and relationships between family members (Johnson et al. 2011). Overall, findings suggest that the amalgamation of stressors and stressful conditions imposed by the COVID-19 pandemic exacerbated experiences of stress on families of autistic children (Ameis et al. 2020; Haidar and Meadan 2024a; Manning et al. 2021; Toseeb 2022).

The pandemic's impact on societal and systemic supports increased the misalignment between demands placed on parents and the resources available to support them increasing adverse emotional repercussions (Aviles et al. 2024; Chen, Byrne, and Vélez 2022), often referred to as parenting stress (Abidin 1992; Deater-Deckard 1998). According to the stress process model, stressors are interconnected and exert mutual influence on one another (Meyer et al. 2022; Pearlin et al. 1981). They can be categorized into primary stressors, encompassing challenges directly linked to caregiving (e.g. juggling work responsibilities while homeschooling children, being cut off from social support), and secondary stressors, which manifest as alterations in both physical (e.g. sensations of exhaustion, pain, irritability) and mental functioning (e.g. emotions of fear, anger, despair).

Amid the COVID-19 pandemic, parents of autistic children experienced both primary and secondary stressors. For example, parents reported experiencing primary stressors such as assuming the role of their child's teachers and therapists (Dhiman et al. 2020; Manning et al. 2021) and reduced external supports due to safety measures (Neece, McIntyre, and Fenning 2020). Parents also reported feeling more isolated (Haidar and Meadan 2024a; Manning et al. 2021) and negative mood changes (Toseeb 2022), secondary stressors. Exposure to stressors imposed by the COVID-19 pandemic influenced parent's perceived stress and wellbeing (Alhuzimi 2021; Corbett et al. 2021; Dhiman et al. 2020; Mazzoni et al. 2022). Particularly, parents of autistic children disclosed more severe consequences related to the pandemic including higher levels of anxiety and stress, disrupted routines, and increased behavioral regulations all influencing the mental health of these parents (Ameis et al. 2020; Colizzi et al. 2020; Dhiman et al. 2020; Ersoy et al. 2020; Ueda et al. 2021). However, some positive influences came from the pandemic such as relief from typical daily challenges, learning about new capabilities of their child with ASD, and utilizing new strategies to involve their child with ASD in family routines (Mumbardó-Adam, Barnet-López, and Balboni 2021; Tokatly Latzer, Leitner, and Karnieli-Miller 2021). Additionally, extra time with family, time to pursue hobbies, a slower pace of learning, and adaptation to virtual social connection, were noted as positive experiences from the pandemic (Chung 2020; Neece, McIntyre, and Fenning 2020).

Although there is extant literature on the experiences of parents of autistic children during the COVID-19 pandemic (see review: Lee et al. 2021), few studies were designed to examine the longitudinal influence of the pandemic utilizing mixed methods (e.g. Asbury and Toseeb 2023; Corbett et al. 2021; Toseeb and Asbury 2023). The unprecedented nature of the pandemic presents a unique opportunity to explore the experiences of parents throughout a period of stress; however, without longitudinal analyses, researchers risk overlooking the non-linear and multi-level factors that shaped individual experiences throughout this period (Wade, Prime, and Browne 2020). Additionally, whereas quantitative studies have documented the elevated levels of parenting stress among parents of autistic children (e.g. Alhuzimi 2021; Chen et al. 2020; Dhiman et al. 2020), qualitative studies often provide more in-depth insights into the lived experiences of parenting stress amongst parents of autistic children throughout the pandemic (e.g. Asbury and Toseeb 2023; Haidar and Meadan 2024a Tokatly Latzer, Leitner, and Karnieli-Miller 2021);

however, few studies have integrated these perspectives (e.g. Haidar and Meadan 2024b; Manning et al. 2021). This study aims to examine the ramifications of the COVID-19 pandemic on parenting stress among parents of autistic children using a longitudinal and convergent, parallel mixed-methods approach (Creswell and Plano Clark 2017; Schoonenboom and Johnson 2017). Quantitatively, we aimed to explore how parenting stress and parenting stress subdomains of parent-child relationship problems, parenting problems, depressive mood, parental role restrictions, and physical health problems developed throughout the shift in COVID-19 restrictions. Qualitatively, we aimed to understand and describe parents' perspective on their parenting stress during the COVID-19 pandemic. By integrating qualitative and longitudinal quantitative findings, we aimed to bridge the gap in the existing literature on parenting stress among parents of autistic children throughout the COVID-19 pandemic through generating mixed-methods meta-inferences (Creswell and Plano Clark 2017). Additionally, much of the research on parenting stress during the COVID-19 pandemic has focused on general measures of wellbeing and stress in parents of autistic children, this study aims to examine as experiences in the context of parental tasks and responsibilities. These insights may aid in discerning areas for targeted support for parents such as assistance in the parent-child relationship, education in implementing effective parenting strategies (primary stressors), or support in effectively managing their mental and physical health (secondary stressors).

Method

Participants & procedures

The sample comprised parents of autistic children (ages 5-22 years) who received professional care prior to the COVID-19 pandemic at one of the three prominent mental healthcare institutions in the Rotterdam region of The Netherlands. The study is part of a broader research project initiated by the Rotterdam Autism Consortium (for the methodological protocol, see Dekker et al. 2022). Data collection occurred during two distinct periods. T1, conducted during the second national lockdown in the Netherlands from January to May 2021, was marked by stringent measures including social distancing, closure of shops, schools, care institutes, and other businesses, restrictions on visits or contact with people outside of the direct family/household, and mandatory outdoor face-mask use (hereafter referred to as 'strict measures'). T2 occurred six months later from September to December 2021, following the relaxation of these stringent measures,

where regulations such as facemask mandates and social distancing were lifted (hereafter referred to as 'relaxed measures') (RIVM 2022). Parents of autistic children were invited to participate, upon providing informed consent, clinical records were checked for eligibility. Subsequently, 68 parents were invited to complete an online questionnaire. Participants were then asked to partake in parent interviews, scheduled approximately 1-2 wk after completing the questionnaires. All 68 parents eligible for participation, regardless of whether they had participated at T1, were invited to complete the surveys at T2. At T1, survey data on parenting stress were provided by 49 parents, while at T2, 39 parents participated. Among the T2 participants, 8 parents had not participated at T1. Data on parenting stress at both T1 and T2 were available for 31 participants, who completed surveys at both times. Additionally, parents invited to complete the online questionnaire were also invited to participate in a parent interview at T1, resulting in a sample of $n = 25$, all of whom had also completed the surveys at T1. Participants received financial compensation for their participation (T1 survey €10; T2 survey €25; T1 interview €25). The Medical Ethics Committee of Erasmus MC Rotterdam approved the study (MEC-2020-0720).

Table 1 presents demographic details of participants at T1 and T2. Notably, in more than a third of families, the child with ASD had one or more siblings diagnosed with clinical conditions, encompassing ASD, Attention Deficit Hyperactivity Disorder (ADHD), or a combination of ASD and ADHD.

Materials

The Parenting Stress Questionnaire (PSQ; Opvoedingsbelastingvragenlijst (OBVL) in Dutch; Vermulst et al. 2015) was used to evaluate parenting stress at T1 and T2. This instrument yields Total Parenting Stress and five subscales' scores. Parent-child Relationship Problems (6 items, T1: $\alpha = 0.89$, T2: $\alpha = 0.90$) measures the degree to which the parent perceives the relationship with the child as stressful and problematic. Parenting Problems (7 items, T1: $\alpha = 0.85$, T2: $\alpha = 0.88$) assesses the degree to which the parent experiences insufficient parenting skills and perceives raising the child as stress-inducing. Depressive Mood (7 items, T1: $\alpha = 0.81$, T2: $\alpha = 0.88$) indicates the degree to which the parents feel unhappy with themselves or their living conditions. Parental Role Restriction (6 items, T1: $\alpha = 0.92$, T2: $\alpha = 0.95$) refers to the degree to which the parents feel restricted in their personal freedom and frustrated in trying to maintain their identity. Finally, Physical

Table 1. Demographic information of sample at T1 and T2.

		T1 (n = 49)				T2 (n = 39)	
		M	SD	n	%	n	%
Age child (years)		12.82	4.62				
Sex child	Female			15	30.6	12	30.8
	Male			34	69.4	27	69.2
Age parent (years)		45.21	7.25				
Sex parent	Female			44	89.8	37	94.9
	Male			5	10.2	2	5.1
Informant role	Biological parent			47	95.9	37	94.9
	Foster parent			2	4.1	2	4.1
Family status	Parents together			35	71.4	28	71.8
	Coparenting			0	0.0	1	2.6
	Single parent			14	28.6	10	25.6
Siblings	No siblings			7	14.3	7	17.9
	Siblings without clinical diagnosis			24	49.0	17	43.6
	Siblings with clinical diagnosis			18	36.7	15	38.5

Health Problems (8 items, T1: $\alpha = 0.84$, T2: $\alpha = 0.85$) measures parent-reported health problems and fitness. Participants responded on a four-point Likert scale ranging from ‘not true’ (1) to ‘very true’ (4). Raw scores were converted to standardized T-scores using norm data for children ages 4-11 and 12-18, respectively. T-scores below 60 are in the normal range, T-scores from 60 to 63 are considered subclinical, and T-scores exceeding 63 fall within the clinical range. The PSQ has demonstrated good reliability and validity (Vermulst et al. 2015). Cronbach’s alphas in the current sample were excellent to good at both times.

Qualitative data were collected through semi-structured interviews conducted with parents at T1 (see Dekker et al. 2022). These interviews consisted of open-ended questions covering various themes, including (A) the subjective experience of the COVID-19, (B) changes observed within the home environment and in the contexts of care and school, (C) the emotional impact on the child, (D) the emotional impact on parents, (E) information- and care-related needs, (F) instances of role confusion, and (G) reflections on the experience of participating in research.

Interviews lasting between 1 to 1.5 h were facilitated through video call software (MS Teams) and were recorded using hardware audio recorders to ensure safe recording and storage on the secure university server. The interviews were conducted by three researchers trained by the second author in conducting experiential semi-structured interviews. The interviews were conducted in the native language of both researchers and participants. A reflexive and sensitive interview style was adopted to validate that questions were comprehended well. Data were transcribed verbatim, and pseudonymized by research assistants before analysis. Analyses were conducted by a team of

researchers who did not conduct the interviews (see [Supplemental materials](#) - Quality Control), using Atlas.ti 22 for Windows.

Design, data analysis, and quality control

A concurrent mixed method design was employed, integrating quantitative analysis of the PSQ and qualitative analysis of parenting stress as articulated in parent interviews. At T1, both quantitative and qualitative data were gathered concurrently, coinciding with a period of strict lockdown measures. Subsequently at T2, a period with relaxed measures, parents completed quantitative measures once again. Analyses were executed concurrently, although qualitative analyses were approached deductively based on the scales of the PSQ. Qualitative analyses are thus independent of, yet supportive to the quantitative analyses and allow for triangulation, explanation, and nuance of quantitative findings at T1 (i.e. triangulation design, Creswell and Plano Clark 2017). Subsequently, quantitative findings at T1 were compared to quantitative findings at T2.

Quantitative analyses

Descriptive analyses employed mean (with standard deviation) and median (with interquartile range) scores to explore how parents of autistic children experienced parenting stress during the COVID-19 pandemic. For all scales except Role Restriction and Total Parenting, Two-way Repeated Measures ANOVA was applied, incorporating one within-subject factor (time) and one between-subject factor (age of child) to analyze the effect of time (T1-T2) and the interaction effect of time x child age on Parenting Stress. Child age groups (5-11 ($n = 17$) vs. 12-22 ($n = 14$)) corresponded to the PSQ norm groups as well as the median split for age based on the total

sample on T1 (4-11 ($n = 24$) vs. 12-22 ($n = 25$)). Given the violation of normality assumptions, Friedman's ANOVA, a non-parametric test, was applied for the scales Role Restriction and Total Parenting. To test for the effect of child age, these analyses were also performed for the two age groups separately. Power analysis using G*Power version 3.1.9.7 (Faul et al. 2009) confirmed that the sample size was adequate ensuring an 80% power to detect a medium effect at a significance level of $\alpha = 0.05$.

Qualitative analyses

First, a research subteam conducted open coding to explore the research question 'How do parents experience their parental load during COVID-19?'. Each researcher individually coded the interviews, which were then discussed in consensus meetings within the subteam and further refined in supervisory team meetings with experienced qualitative researchers. Consensus codes were established in these meetings, iteratively refining the conceptualization of 'parenting stress' (Willig 2008). Second, deductive thematic analysis traced the occurrence of the PSQ scales in the consensus-based codes (Braun and Clarke 2006). Third, consensus codes were organized into subthemes within PSQ-based main categories. Fourth, the style of speaking or participants within each theme was analyzed to add nuance to the subthemes (Braun and Clarke 2006). This involved considering not only what was articulated but also the absence or limited prominence of specific themes, variation within themes, and conflicts in overt and implicit experiences. Fifth, themes were written by FT and cross-checked by EvR and OW. The themes are organized by scale to facilitate mixed-method integration, with each scale encompassing reflections on speaking style, theme prominence, and narrative descriptions of each subtheme. The [online appendix](#) provides an overview of main themes and subthemes, accompanied by corresponding quotes from the interview material (in-text codes correspond with codes in the [online appendix](#)).

Integration of quantitative and qualitative results

The quantitative and qualitative results were integrated in line with the guidelines from Younas, Durante, and Fàbregues (2023). This process entailed summarizing the key quantitative and qualitative results for each domain, along with selected quotes and meta-inferences. The meta-inferences were categorized according to the guidelines of Fetters, Curry, and Creswell (2013). According to Fetters, Curry, and

Creswell (2013), the 'fit' of data integration results in three possible outcomes: confirmation, expansion, and discordance. Confirmation occurs when the findings from one type of data (e.g. quantitative) align with and validate the findings from another type (qualitative). Expansion involves findings that provide additional depth or breadth by exploring distinct dimensions of the same phenomena or by describing complementary perspectives of a central phenomenon of interest. Finally, discordance arises when results from different data types are inconsistent with one another.

Reflexivity

Qualitative analyses were conducted by a team that was assembled with a balanced variation in affiliations and experience with the target phenomenon (ASD) and qualitative research (Willig 2008). The team consisted of 3 master students, 3 junior research assistants (LB, IvdH, RL), 1 graduate student (OW), 2 senior researchers with basic training in qualitative research (LD & EvR), and 1 senior researcher (FT) with extensive experience in qualitative research. Of the senior researchers, 1 had expertise in ASD (LD), one in parenting stress (EvR), and one in qualitative research in clinical psychology (FT). The junior researchers were trained in different universities over the world (Netherlands, Germany, USA) and were from various racial and SES backgrounds. Only the three senior researchers are parents of (young) children (with and without special needs), and experienced parenthood during the pandemic.

Results

Quantitative results

Descriptive statistics for participating parents and their autistic children can be found in [Table 1](#). Most parents were female (89.8% at T1; 94.9% at T2) and their autistic children were predominantly male (69.4% at T1; 69.2% at T2) with a mean age of 12.82 at T1. Neither the child's gender nor age significantly influenced the PSQ scales at T1 and T2. To assess potential selective dropout between T1 and T2, comparisons of the PSQ scales were made between parents who only participated at T1 ($n = 18$) and those who participated at both T1 and T2 ($n = 31$). Parents who only participated at T1 reported lower Parenting Problems at T1 ($M = 51.89$, $SE = 2.57$) compared to those who participated at both T1 and T2 ($M = 58.42$, $SE = 1.95$). This difference was significant: $t(47) = -2.02$, $p = 0.048$, indicating a small-sized

effect ($r=0.028$). Nevertheless, both groups' scores were in the normal range at T1, thereby minimizing the risk of attrition bias. No significant differences were found for other PSQ scales.

Table 2 presents parent-reported parenting stress at both T1 and T2. Initially, parents reported subclinical levels of Parent-child Relationship Problems at T1, indicating mild stress related to their child. By T2, these scores had shifted to the normal range. Parenting Problems and Depression scores remained within the normal range at both time points, indicating that parents felt adequately skilled in their parenting abilities and generally content with their life circumstances. Parental Role Restriction scores were consistently in the clinical range at both T1 and T2, reflecting significant feelings of restriction in personal freedom and identity due to parental responsibilities. Notably, the bimodal distribution of this subscale indicated a distinct subset of parents experiencing low levels of role restriction. For Physical Health problems, scores were subclinical at T1, but elevated to clinical levels at T2, indicating respectively mild and severe problems in fitness and health experiences. Finally, Total Parenting Stress remained in the subclinical range at both time points, indicating overall mild stress levels.

Table 3 presents the results of descriptive statistics and ANOVA results of parenting stress among participants who participated at both T1 and T2 ($n=31$). The analysis revealed a significant effect of time on Parent-child Relationship Problems, $F(1,29) = 8.26$, $p=0.008$, indicating that parents experienced fewer problems in the relationship with their child at T2 compared to T1. No significant temporal effects were observed for Parenting Problems ($F(1,29) = 1.05$, $p > 0.05$), Depressive Mood ($F(1,29) = 0.005$, $p > 0.05$), Parental Role Restriction ($\chi^2(1) = 0.048$, $p > 0.05$), Physical Health Problems ($F(1,29) = 1.794$, $p > 0.05$), or Total Parenting Stress ($\chi^2(1) = 0.000$, $p > 0.05$), indicating no significant changes within these subdomains from T1 to T2. Additionally, no significant interaction between time and child age was found for Parent-child Relationship Problems,

Parenting Problems, Depressive Mood, or Physical Health problems. Separate Friedman's ANOVA analyses for age groups 5-11 years and 12-22 years also yielded no significant effects, indicating that the way parents experienced parenting stress at T2, compared to T1, was not related to the age of their children.

Qualitative results

Select participant quotes can be found in Table 4. For a more detailed selection of illustrative quotes, please refer to the [online appendix](#).

Parent-child relationship problems

Parents rarely spontaneously or implicitly reported relational problems with their child suggesting that these issues were neither prominent nor substantially changed during the COVID-19 pandemic. Most parents reported that their pre-pandemic ability to 'read and write' [Q1.1] with their child helped to support family functioning. Notably, parents reported that family dynamics became both closer [Q1.2] and more balanced [Q1.3], due to an increased emphasis on family structure, including shared meals and activities, and fewer external impulses [Q1.4]. This allowed parents to organize daytime routines sensitive to the child's needs with fewer disruptions from external stressors or changes in environment.

Parenting problems

In contrast to relationship issues, parenting problems were more commonly reported and discussed explicitly. The most prevalent issue within the parenting problems subdomain was described in relation to children's academic requirements. Parents reported a struggle [Q2.1] to motivate their child to complete schoolwork without assuming the role of the teacher. Parents felt that their children appeared confused by the crossover [Q2.1.1] between school and home. A subtheme of academic challenges appeared associated with potential role confusion [Q2.2]. For example, parenting problems increased when a child objected that the mother is not the teacher. Additionally,

Table 2. Parenting stress on T1 and T2.

	T1 ($n=49$)			T2 ($n=39$)		
	<i>M</i> (SD)	<i>Md</i> (IQR)	Label ^a	<i>M</i> (SD)	<i>Md</i> (IQR)	Label ^a
Parent-child Relationship Problems	60.08 (9.47)	61 (14)	Subclinical	59.21(10.07)	58 (16)	Normal
Parenting Problems	56.02 (11.21)	56 (16)	Normal	56.36 (12.03)	56 (19)	Normal
Depressive Mood	59.31 (8.55)	60 (14)	Normal	59.07 (9.92)	60 (15)	Normal
Parental Role Restriction	64.63 (11.99)	66 (23)	Clinical	64.33 (12.15)	66 (26)	Clinical
Physical Health Problems	62.49 (8.98)	64 (16)	Subclinical	64.59 (7.84)	65 (13)	Clinical
Total Parenting Stress	62.71 (9.31)	61 (14)	Subclinical	62.95 (11.28)	65 (16)	Subclinical

Note. ^aBased on average score. Md: Median; IQR: Interquartile Range.

Table 3. Effect of time and child age on parenting stress.

	Repeated Measures ANOVA statistics				
	M (SD) T1	M (SD) T2	F (1,29)	p-value	Partial η^2
Parent-Child Relationship	61.81 (8.98)	59.16 (9.78)			
Within-Subject Effects					
Time			8.26	.008 ^a	.222
Time x Child Age			.005	.942	.000
Between-Subject Effects					
Child Age			.005	.945	.000
Parenting Problems	58.42 (10.83)	57.25 (11.84)			
Within-Subject Effects					
Time			1.05	.315	.035
Time x Child Age			.467	.500	.016
Between-Subject Effects					
Child Age			.011	.916	.000
Depressive Mood	58.94 (8.38)	59.03 (10.38)			
Within-Subject Effects					
Time			.005	.943	.000
Time x Child Age			2.68	.113	.085
Between-Subject Effects					
Child Age			1.55	.224	.051
Physical Health Problems	63.71 (8.26)	65.16 (10.67)			
Within-Subject Effects					
Time			1.79	.191	.058
Time x Child Age			.207	.653	.007
Between-Subject Effects					
Child Age			1.70	.202	.055
	Friedman's ANOVA statistics				
	Md (IQR) T1	Md (IQR) T2	Test Statistic (χ^2)	p-value	Effect Size (Kendall's W)
Parental Role Restriction					
Time (total sample)	66.00 (26.00)	66.00 (26.00)	.048	.827	.002
Time (age 4 to 11 years)	70.00 (22.00)	70.00 (20.50)	.000	1.00	.000
Time (age 12 to 22 years)	57.50 (19.00)	57.50 (26.00)	.111	.739	.008
Total Parenting Stress					
Time (total sample)	63.00 (14.00)	66.00 (13.00)	.000	1.00	.000
Time (age 4 to 11 years)	68.00 (12.00)	66.00 (9.50)	.059	.808	.003
Time (age 12 to 22 years)	61.00 (17.75)	63.00 (23.00)	.077	.782	.005

Note. ^aSignificant at $p < .01$. Md: Median; IQR: Interquartile Range.

parents did not tend to identify [Q2.2.1] with the teacher role and handled the parenting problem of motivating children to complete their schoolwork by giving the task back to the teacher.

In most cases, parents 'solved' the problem by lowering the pressure on schoolwork throughout the duration of the lockdown. Despite concerns about falling behind, many parents reported that it was more important [Q2.1.2] to keep their children regulated than to keep up with schoolwork. However, most parents felt pressured [Q2.1.3] by the school to aid their child in completing their schoolwork. In a minority of cases the school appeared supportive of parents' struggles. For example, a teacher allowed a child to sit in the classroom with him while teaching virtually to the other students. Another example was that teachers made a video showing the school being closed and again when the school was reopened to reduce confusion for the children.

Parents also made explicit distinctions [Q2.3.1] between specific parenting struggles and more general

relationship problems. Such explicit distinctions emphasize the intricate relationship between the domains. For example, when parents cope with discussions with their child by giving in, this decision is often motivated by a desire to maintain overall relationship harmony.

On a positive note, most parents reported that their regular ways of adjusting parenthood [Q2.4] to their children's special needs helped with coping with the COVID-19 measures. Daily routine charts, pictograms, and other types of visual language and structure were utilized by the entire household. Across the spectrum, parents reported that their usual ways of organizing day-to-day structure and keeping the changes between contexts as straightforward as possible helped to keep parenting problems to a minimum.

Depressed mood

Quantitatively, the PSQ utilizes the subscale of 'depressed mood' to explore the extent to which a parent is (un)happy with oneself and one's living

Table 4. Joint display of key quantitative and qualitative results.

Domain Parenting Stress	Quantitative results T1 and T1-T2	Qualitative results T1	Supporting quotes	Mixed Methods Meta Inferences
Parent-child Relationship Problems	Subclinical problems at T1. Normal range at T2. Parents experienced fewer problems in the relationship with their child at T2 compared to T1 ($F(1,29) = 8.26, p = .008$)	Parents generally reported no significant relational problems with their child during the COVID-19 pandemic. Many credited their pre-pandemic adaptive abilities as a foundation for supporting family functioning. Improved family dynamics during COVID-19 were attributed to stronger family bonds, a more balanced and consistent family structure, and the benefits of reduced external disruptions and changes in context.	"We already were very close, very ... I can read him completely. [...] I don't think that that changed a lot. I have always been his mediator to the outside world because he looks at me like 'mom, help', so I only need one look and I know, okay. [...] And, well, that's what I have done his whole life, so our bond is very close and strong." (Quote 1.1, Interview 8)	Expanded: At T1, parents reported subclinical problems quantitatively, which were often framed qualitatively as manageable challenges for which their experience had already prepared them well. Additionally, parents emphasized the positive effects of COVID-19 restrictions on family dynamics. The quantitative decline in parent-child relationship problems observed from T1 to T2 may reflect the adaptive capacity of these parents.
Parenting Problems	Normal range at both T1 and T2. No effect of time	Parenting challenges, especially around academic requirements, were commonly reported. Parents struggled to motivate their children to complete schoolwork without taking on the teacher role, leading to confusion between school and home. Many parents lowered academic pressure, prioritizing their child's regulation over keeping up with schoolwork, though most felt pressured by schools to assist. Role confusion emerged when children resisted parental authority in academics, with some parents explicitly distinguishing parenting struggles from relationship issues. Parents utilized visual aids like charts and pictograms, creating consistent structures to minimize parenting problems.	"He thinks: 'school is school, home is home'." (Quote Q2.1.1, Interview 3) "But when it leads to so many meltdowns, and you so your child spiraling down to zero, well ... [...] I will not lie, it was really terrible. [...] I did not see those severe meltdowns in him since he was four ... [...] Well, then I am really capable of saying: never mind with school, for now" (Q2.1.2, Interview 6)	Expanded: Qualitatively, parents revealed significant efforts to address role confusion, make bold decisions that defied expectations, prioritize their child's well-being over academic achievement, and provide structured approaches, all to minimize parenting problems, which were quantitatively in the normal range.
Depressive Mood	Normal range at both T1 and T2. No effect of time	Most parents reported feeling more at ease, benefiting from reduced pressure and more quality family time. While many parents accepted their role restrictions, some felt isolated and lonely, with these feelings intensified by COVID-19 measures. Almost all parents spoke in an upbeat tone of voice, however reflecting on the pandemic with a "what if" mindset. They were proud of managing	"Especially in the second lockdown, I became so much more aware of the loneliness. [...] Sitting inside, no human connections. It is breaking me" (Q4.2.2, interview 6) "We got through last year with a lot of creative effort. So, yes, if we should have to do that another time ... without holiday care, like having the boys at home for six weeks. I would just not be able to bare that.	Discordant: Although, in line with quantitative results, parents rarely reported depressive feelings explicitly. The Covid pandemic seemed to have enlarged existing patterns of depressed mood, with some mentioning feelings of loneliness and isolation. Many also described how the balance had often just remained and how small changes could have been catastrophic. While often expressed in

(continued)

Table 4. Continued.

Domain Parenting Stress	Quantitative results T1 and T1-T2	Qualitative results T1	Supporting quotes	Mixed Methods Meta Inferences
		the challenges but acknowledged that small changes could have worsened their situation.	[...] They just have to understand the other side: that that will lead to other problems. You get exhausted, you won't be able to cope with it anymore, and at some point, you will just collapse. And then what?!" (Quote 4.4, Interview 20)	an upbeat tone, these 'what if' thoughts reflected the underlying worries these parents experienced.
Parental Role Restriction	Clinical problems at both T1 and T2. The bimodal distribution indicated a distinct subset of parents experiencing low levels of role restriction. No effect of time	Parents frequently reported role restriction, including limited ability to attend outings, travel, or maintain a social life. Many reduced or stopped working to manage their child's care. During COVID-19, the slower pace of life brought relief, reducing pressure, shame, and fear of missing out, as the world seemed to adapt to their lifestyle. However, the lockdown also intensified restrictions, as parents lost small personal moments, like grocery trips or waiting at care facilities, that previously offered brief respites.	"Well, we have autistic children, so we could not take them anywhere, which was always ... hard. So, the fact that I could never go anywhere [due to covid] was nicely aligned with that we cannot take our kids anywhere anyway." (Quote 3.2.1, Interview 12) "So at times, I worried, 'how long will this last?' as normally in the summer holidays, she can go to this care farm for a week. And then it seemed that that would be canceled too, and I really worried like, how will I then get through? Like, get through those six weeks of summer?" (Quote 3.3, Interview 13)	Confirmed: The clinical problems reported quantitatively were confirmed qualitatively. In some cases, the pandemic alleviated negative feelings related to role restriction, such as pressure, shame, and fear of missing out, that parents had experienced pre-pandemic. Similarly, the quantitative data indicated that some parents experienced low levels of role restriction.
Physical Health Problems	Subclinical problems, scores at T1. Clinical levels at T2. No effect of time	A significant portion of the sample reported general health issues, such as diabetes, surgeries, and respiratory diseases. However, these health problems were rarely explicitly linked to parenting stress. The main health concern tied to parenting was fatigue or exhaustion. Parents did not report direct health issues due to COVID-19, though many with pre-existing conditions expressed concerns about the impact of contracting the virus on their ability to care for their child.	"I noticed that I was extremely exhausted" (Quote 5.2, Interview 3) "And of course, I am alert to not get infected, because when I would get sick, who would be there to help him?" So yeah, I keep going, I would always keep going" (Quote 5.3, Interview 8)	Confirmed: The subclinical and clinical problems reported quantitatively were confirmed qualitatively. Although parents often did not explicitly link them to parenting stress, they did report fatigue and exhaustion, in addition to general health issues. They also reported fear of COVID-19 because of care duties, seemingly prioritizing their child's well-being over their own health.

conditions (Vermulst et al. 2015). As such, the scale 'depressed mood' was coded in a broad sense encompassing a range of emotions with depressive elements, such as fear for the future, fear of the virus, lack of pleasure, or mood imbalance in parents. Depressed mood was rarely reported explicitly. Parents reported feeling more at ease because they experienced less pressure and more uninterrupted quality time with their family.

The depressed mood domain seemed to show many 'enlargements' of pre-covid experiences. On the one hand, many parents showed an accepting attitude, which seemed to align with an accepting stance [Q4.2.1] towards role restrictions that parents were used to before COVID. On the other hand, some parents reported that their life as a parent of a child with ASD – including the prominent role in facilitating care – encompassed feelings of isolation and

loneliness [Q4.2.2]. These feelings were enlarged during COVID due to safety measures increasing social isolation.

However, even for parents who did report depressive experiences, it was striking that almost all parents answered in an upbeat [Q4.3] tone of voice. These parents often responded in a ‘what if’-style [Q4.4]. For example, they reported that they made it through the challenges of the pandemic and were proud of that (hence the positive tone of voice) but also realized that if only one or a few minor details would have been different, they might have tipped over the edge. These parents also expressed worries about their child’s potential loss of skills and challenges related to life ‘going back to normal’ after the pandemic [Q4.5].

Role restriction

Role restriction is one of the most explicitly voiced experiences across interviews. Most parents reported role restriction [Q3.1.1], which is typical in parents of autistic children. Examples range from the inability to attend (spontaneous) outings, activities or birthday parties to the impossibility of travelling or sustaining a social life with friends and family. It is important to note that the sample contains a relatively large portion of parents who reduced or stopped working [Q3.1.2] to manage the care of their child.

During COVID-19-times, many parents reported a sense of relief that social life slowed down. For example, there were no birthday parties to attend or spontaneous outings, and everyone generally stayed at home. Several parents reported that even though their role restriction did not change, they felt less pressure [Q3.2.1], shame [Q3.2.2], or sense of missing out [Q3.2.3]. In a way, parents explained, the world adapted more to their standards than the other way around. Observing that parents in their social circle struggled tremendously with enforced role restrictions added both a sense of relief and a sense of pride about their creativity and flexibility at regular times.

Opposite to this more explicit report of reduced pressure in role restriction, parents also reported a difference in role restriction as their already limited moments for themselves caved [Q3.3] in COVID-19 times. For example, prior to the pandemic, parents who had reduced or stopped working to take care of their children utilized times during grocery shopping or waiting in the lobby of care facilities as little moments ‘for themselves’, that allowed them to catch a breath. With children being at home due to the

lockdown, stores being closed, and care being conducted digitally, these little moments disappeared.

Health problems

A substantial portion of the sample experienced general health problems, ranging from diabetes, surgeries, and respiratory diseases. However, the health problems reported in the interviews were seldom (explicitly) related to parenting stress [Q5.1.1]. The only health complaint that appeared to be related to parenting was tiredness or exhaustion [Q5.2]. Parents did not report any concrete health problems due to COVID-19; apart from being in an ‘at-risk group’ for COVID-19-infection due to pre-existing health problems [Q5.1.2]. However, all parents with pre-existing health problems expressed concerns that contracting COVID-19 would negatively impact care for their child [Q5.3].

Integration of quantitative and qualitative results

Whereas quantitative results indicated stable or reduced stress levels in some areas, qualitative findings highlighted subtle differences in parental experiences. Through integrating the results, findings of the qualitative reports of parents reflect discordance, expansion, and confirmation of the quantitative results (see Table 4). Of note, the qualitative results related to the domains of parent-child relationship problems and parenting problems expanded on the quantitative findings. Qualitative reports of depressive mood were discordant from the quantitative results. Parents qualitative inputs on parental role restriction and physical health problems aided in confirming the quantitative results.

Discussion

This study investigated parenting stress and the lived experiences of Dutch parents of autistic children during both a strict lockdown period (T1) and a subsequent period of relaxed restrictions (T2). Utilizing a longitudinal, mixed-method approach, this study supports and adds to previous literatures understanding of parental stress among parents of autistic children during the COVID-19 pandemic (e.g. Alhuzimi 2021; Asbury and Toseeb 2023; Chen et al. 2020; Dhiman et al. 2020; Haidar and Meadan 2024a; Haidar and Meadan 2024b; Manning et al. 2021; Tokatly Latzer, Leitner, and Karnieli-Miller 2021) critical for refining supports and policies for parents of children with and without ASD.

In line with the experiences of parents generally (see reviews: Chung et al. 2024; Fadda et al. 2022), the results of this study also demonstrate the positive and negative experiences of parents during the COVID-19 pandemic. Within this study, parents of autistic children quantitatively reported normal to clinical levels of parenting stress which remained generally stable over the study, except for challenges associated with the parent-child relationship. Consistent with previous literature, qualitatively, parents described how certain stressors intensified, like homeschooling demands and changing rules (Dhiman et al. 2020), while others, such as the stress of social obligations lessened (Mumbardó-Adam, Barnet-López, and Balboni 2021). Furthermore, parents discussed their ability to lean on pre-existing coping skills developed before the pandemic, which aided in navigating a world that does not perfectly accommodate their child's unique needs supported them during the pandemic. Using the stress process model (Pearlin et al. 1981), it appears that parents of autistic children may navigate primary stressors, those directly related to caregiving responsibilities, such as difficulties within the parent-child relationship and parenting problems, more adeptly than secondary ones, which include the broader impact of stressors on mental and physical well-being, encompassing depressive mood, role restriction, and physical health concerns (Deater-Deckard 1998; Pearlin et al. 1990).

Parents of autistic children appeared to adapt well to primary and secondary stressors during the pandemic, as noted in the stability of parenting stress across subdomains, except parent-child relationship problems, from T1 to T2. The substantial quantitative decline in reports of parent-child relationship problems from T1 to T2 suggested a positive shift in the parent-child relationship over the study period. The decrease in parent-child relationship problems aligns with previous literature noting improved parent-child relationships within this population (Bolbocean et al. 2022; Tokatly Latzer, Leitner, and Karnieli-Miller 2021). The decline in parent-child relationship problems may be related to parents effectively adapting to and overcoming a temporary peak in parenting stress triggered by the COVID-19 pandemic or due to the reduction in the COVID-19 safety restrictions. Qualitative results highlighted how increased familial closeness contributed to fostering harmony within families during the pandemic. While quantitative results indicated normal stress levels regarding parenting problems at both T1 and T2, qualitative reports expanded on these findings by highlighting the

significant efforts parents had to make to prevent stress related to parenting problems, particularly when balancing parental and teaching responsibilities during homeschooling. Additionally, parents discussed how skills developed prior to the pandemic such as their ability to adapt routines with flexibility and creativity was beneficial in navigating the societal changes and new demands of the COVID-19 pandemic. Similar studies found that parent's ability to quickly and creatively adapt to the pandemic aided in coping with the significant changes brought about by the pandemic (Mumbardó-Adam, Barnet-López, and Balboni 2021; Tokatly Latzer, Leitner, and Karnieli-Miller 2021). Overall, parents appeared to adapt well to primary stressors.

In contrast, secondary stressors such as role restriction, depressive mood, and physical health issues proved more enduring. Quantitative findings revealed that parenting stress associated with role restriction persisted within the clinical range at both T1 and T2. Qualitatively parents reported feelings of restriction in personal time and social life related to the sacrifices made caring for their children. Although quantitatively, parents did not report increased levels of depressed mood, qualitatively, they mentioned experiencing increased feelings of loneliness and isolation with many describing how even slight changes or the continuation of measures might have worsened these feelings. Previous studies found that support from partners or family members was protective against feelings of role restriction and isolation (Alhuzimi 2021; Amorim et al. 2020; Manning et al. 2021). Difficulty in finding these external supports throughout the pandemic may have made it more difficult for parents to manage their responses to these secondary stressors. Additionally, parents appeared to primarily focus on the care of their children rather than their high levels of physical health problems. Qualitative data revealed that parents did not directly attribute their physical health problems to parenting stress, but rather expressed concerns about contracting the COVID-19 virus out of fear about who would care for their child. In addition to fears related to contracting the COVID-19 virus themselves, researchers found that parents feared for their child contracting the COVID-19 virus (Manning et al. 2021).

Limitations and future directions

This study developed throughout the COVID-19 pandemic. Several limitations necessitate acknowledgement. Firstly, recruitment occurred during a period of

increased stress, potentially introducing selection bias. To address this concern, clinical sampling was employed. An examination of selection bias at T2 indicated it was not a significant concern. Secondly, it is crucial to recognize limitations associated with participant demographics. The majority of participants were mothers with a partner, reporting on their autistic, assigned male at-birth child. While such demographic breakdowns are common in parental experience and ASD research, further research into the experiences of other caregivers and assigned female at-birth autistic children is imperative for a comprehensive understanding of the parenting experience across all demographic factors (Halladay et al. 2015). Additionally, the studies small sample size is a limitation. Utilizing a larger sample size would enhance the robustness and generalizability of the findings. It is essential to acknowledge that this study was conducted in the Rotterdam region of the Netherlands, which may limit the applicability to other cultural or regional contexts. Finally, three individuals conducted interviews with the participants. The potential slight differences in methods and perspectives should be considered; however, all interviewers underwent the same training. Nonetheless, the insights and themes generated by this study can be extrapolated to enhance understanding of the impact of crises on parenting stress more broadly (Levitt 2021).

Implications

The COVID-19 pandemic provided a unique opportunity to examine the parenting stress of parents of autistic children. By employing a mixed-method design with multiple data collection periods, this study has uncovered a deeper understanding of how the pandemic has impacted the parenting stress across various subdomains. Particularly in times of increased stress and diminished support, such as the COVID-19 pandemic, focus on supporting parents is critical as parental wellbeing is associated with overall family functioning and has influences on the quality of care they provide for their children (Johnson et al. 2011; Lim et al. 2020). Additionally, increased stress has been associated with adverse outcomes, including compromised mental and physical health, increased mortality risk, obesity, autoimmune disorders, and susceptibility to infectious diseases (van der Lubbe et al. 2024; Warreman et al. 2023), thereby underscoring the urgent need for enhanced support for these caregivers. For parents of autistic children this is

particularly important as these parents often experience higher rates of parental stress compared to parents of non-autistic children (Hayes and Watson 2013).

These findings highlight the importance of addressing both primary and secondary stressors faced by parents of autistic children; however, parents demonstrated fewer positive effects on secondary stressors underscoring the importance of interventions to target secondary stressor domains such as role restriction, physical health, and depressive mood, which are crucial in alleviating the overall stress experienced by parents (Anthony and Campbell 2020). Prioritizing the mental and physical well-being of parents is paramount, considering their significant caregiving role in the lives of autistic children. A deeper understanding of parental stress during crises enables social support services to be tailored to the unique needs of parents, ultimately fostering resilience for both autistic children and their families beyond the pandemic.

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Ethical approval

This study was evaluated by the Medical-Ethical Committee of the Erasmus Medical Centre Rotterdam, The Netherlands (MEC-2020-0720). All participants signed full Informed Consent to analysis, sharing and publication of their data, under condition of anonymization and/or pseudonymization based on the Data Management Plan approved by the Data Steward of Erasmus University Rotterdam, ESSB.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Data availability statement

All materials, methods and syntaxes are available for sharing *via* open science framework. Quantitative and pseudonymized qualitative can be shared under the conditions outlined in the Data Management Plan (Creative Commons license CC BYNC-SA 4.0 Attribution-NonCommercial-ShareAlike 4.0 International). Requests for sharing data can be addressed to the Principal Investigator (Dr. L. P. Dekker, the Rotterdam Autism Consortium).

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