#### RESEARCH



## Parental Stress and Quality of Life in Parents of Young Children with Autism

Leanne Dijkstra-de Neijs<sup>1,2</sup> · Daphne B. Boeke<sup>1</sup> · Ina A. van Berckelaer-Onnes<sup>1,2</sup> · Hanna Swaab<sup>1,2,5</sup> · Wietske A. Ester<sup>1,3,4</sup>

Accepted: 4 March 2024 © The Author(s) 2024

#### **Abstract**

Parents of children with ASD are at risk for chronic stress due to challenging parenting. It is unknown whether stress is already present in early parenthood, similar for mothers and fathers and if this impacts quality of life (QoL). Parental stress and QoL were assessed in 56 mothers and 51 fathers of young children (aged 3 to 7) with autism. Associations between parental stress (OBVL) and QoL (WHOQoL-BREF) were examined. Parents of young children with ASD appear to have high parental stress from conflicting feelings towards their child and from difficulties with parenting. Mothers have higher stress from feeling confined in their motherly role than fathers compared to the OBVL norm population. Both mothers and fathers have a low QoL. Increased maternal conflicting feelings towards the child associated with lower psychological QoL, while high maternal feelings of role confinement associated with low physical QoL. Increased paternal conflicting feelings towards their child related to lower physical and social QoL, while fathers with more parenting difficulties reported less satisfaction with their psychological and environmental wellbeing. Thus, already at young age, parenting children with ASD is a major challenge for both mothers and fathers.

**Keywords** Parental stress · Quality of life · Autism · Young children

#### Introduction

Parents of children with ASD are at risk for chronic stress due to challenging parenting [14, 27], which may affect their quality of life (QoL). Most of the parenting stress-related research has been conducted in mothers of school aged children and less is known about the stress of parents of young children with ASD, the stress levels of fathers, and the impact of their parenting stress on QoL.

It is known that mothers of school aged children with ASD experience 1.5-times higher levels of daily parenting stress [27], present more stress-related mental and/or physical problems and have an elevated mortality hazard ratio compared to mothers of typically developing children [20, 27, 40, 41, 46, 58]. Increased parental stress in children with ASD is found to be related to attuning to the child's special needs [32, 40]. In addition, the lack of adequate reciprocity, a primary symptom of autism, may result in parents experiencing the interaction with their child as emotionally challenging, compared to parents with typically developing children [2, 34, 40, 55]. Although parental stress has been extensively studied as an independent, outcome and mediator variable in ASD research and recent studies have shown that parents of children who have not yet been diagnosed with ASD already experience increased stress levels compared to parents of typically developing children [12, 52], the question is still underexposed whether parental stress is already present in parents of young children with ASD. During this stage of life, the external demands are less challenging for the child than at a later age

 □ Leanne Dijkstra-de Neijs l.dijkstra@youz.nl

Published online: 09 May 2024

- Sarr Autism Rotterdam, Youz Child- and Adolescent Psychiatry, Parnassia Group, Dynamostraat 18, 3083 AK Rotterdam, The Netherlands
- <sup>2</sup> Clinical Neurodevelopmental Sciences, Leiden University, Leiden, The Netherlands
- Parnassia Group, Parnassia Academy, Den Haag, The Netherlands
- <sup>4</sup> Curium-LUMC, Department of Child- and Adolescent Psychiatry, Leiden University, Oegstgeest, The Netherlands
- Leiden Institute for Brain and Cognition, Leiden University, Leiden, The Netherlands



when developmental challenges become more complex. The few studies that did address parental stress at an early age, showed that parents, mostly mothers, of children with ASD aged 2 to 5 report more overall parenting stress than parents of typically developing children or children with a developmental delay. Therefore, more attention is needed to explore the mechanisms inducing stress [17–19, 23]. Parenting demands may not only lead to high parental stress, it can also lead to more pronounced behavioral problems in children [22, 45, 57], due to children's response to parental stress. Conversely, behavioral problems in the child can induce parental stress [39, 57]. It is therefore crucial to obtain better insight into parental stress in parents with young children with ASD. Associated to the question about parental stress in parents of young children with ASD, is the question of the impact of raising a young child with ASD on the QoL in their parents. Studies in parents of older school aged children show that parental stress is associated with a decreased overall QoL [13, 30, 53]. Specifically, family functioning [31] and parental physical wellbeing are affected [29].

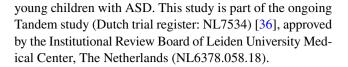
Most studies on parental stress in children with ASD focus on mothers, and not on fathers [21]. Consequently, much less is known about fathers' coping strategies while parenting a child with ASD [43]. Results of studies of parents raising children with ASD that do include fathers are often based on small sample sizes, do not differentiate for gender during analyses or include parents from different families [24], hindering comparison between fathers and mothers. The few studies that did explore the differences between mothers and fathers, found varying results [3, 21, 24, 38, 42, 47]. Learning about differences between parental experiences of fathers and mothers may help to understand mechanisms regarding parent factors that impact parental mental well-being and consequently also the well-being of their children.

With respect to parental stress, it is important to understand the impact of specific stress inducing factors, like interaction related factors or factors related to the impact of the extra effort that is needed from parents, and their effect on different domains of parental QoL in both mothers and fathers of young children with ASD. The current study aims to examine the question whether high parental stress and low QoL is already present in both mothers and fathers of young children with ASD and explores whether maternal and paternal stress impact parental QoL.

#### **Methods**

#### **Study Design**

The present study is a descriptive, correlational, cross-sectional study assessing parental stress and QoL in parents of



#### **Participants**

Parents were eligible for inclusion if (1) their child was diagnosed with ASD, and (2) the child was aged 3 to 7 years. Parents were recruited from Youz Parnassia Group and GGZ Delfland, both mental health care providers in the Netherlands. Parents eligible for inclusion were asked by their child's psychologist for consent to be contacted by the research team shortly after their child being diagnosed with ASD. If parents agreed, contact details of the parents were passed on to the research team. The research team then screened the parents by telephone to verify whether they met the inclusion criteria and if they were willing to participate. If they did, an informed consent meeting took place where parents received detailed information about their study participation and signed an informed consent form. After informed consent, a research employee provided parents with a link with which they could enter explanation about the study and complete their questionnaires within Research Manager, a data management program. If parents had questions about the questionnaires, they could contact an employee of the research team by mail or telephone. No incentives for participation were given. In total 107 parents (56 mothers and 51 fathers) of 61 children were recruited.

#### Measures

#### **Parental Stress**

Parental stress was assessed by self-report on three areas of parental stress using the Dutch parenting burden questionnaire (in Dutch: Opvoedbelasting Vragenlijst, OBVL [51]). This questionnaire assesses stress related to (1) parental conflicting feelings towards the child, represented by the degree to which the parent has compromised feelings/ thoughts about the child for example 'I feel happy with my child' (6 items); (2) difficulties with parenting, concerning the extent to which the parent feels they doubt to have enough skills in the upbringing of their child, for example 'My child listens to me' (7 items), and (3) the extent to which the parent experiences the parental role as confining, for example 'Because of my child's upbringing, I don't get enough time for myself' (6 items) [51]. The OBVL uses a 1–4 response scale (1 = does not apply, 2 = does somewhat apply, 3 = does apply, 4 = totally does apply). Raw scores are transformed into T-scores which give clinical meaning using norm tables, as presented by Vermulst et al. [51] (see "Appendix 1"). Explorative factor analysis has shown that



the three theoretically assumed parental stress areas within the OBVL are empirically demonstrated [51]. The concept validity of the three parental areas is good. The norm population used within this study is the OBVL norm population [51]. The norm population included data on 848 mothers of typically developing Dutch children (50.8% boys) from the general population [51].

#### **Quality of Life**

QoL was assessed using parental self-report on four scales of the World Health Organization Quality of Life (abridged version) questionnaire (WHOQoL-BREF), including: (1) 'physical health', incorporating activities of daily living, energy and mobility (7 items); (2) 'psychological health', incorporating bodily image, feelings and self-esteem (6 items); (3) 'social relationships', including personal relations, social support and sexual activity (3 items); (4) 'environment', including financial resources, health- and social care and home environment (8 items) [56]. The WHOQoL-BREF is frequently used to assess QoL in a variety of situations and populations [48]. This self-report questionnaire includes 26 items with a 1-5 response scale (1 = not at all, 2 = almost not, 3 = average, 4 = pretty good, and 5 = completely). An item example is: "How much do you enjoy life?" A higher domain score (min = 1 and max = 100) corresponds to a better QoL. Clinical outcomes on the WHOQoL-BREF can be interpreted as "excellent", "very good", "good", "fair" or "poor" satisfaction with someone's QoL, see "Appendix 2" [26]. Internal consistency, item-total correlations, discriminant validity, and construct validity through confirmatory factor analysis indicate good to excellent psychometric properties of reliability and tests of validity [44, 48]. The WHOQoL-BREF is a cross-culturally valid assessment but unstandardized questionnaire of QoL [44, 48]. Normative values obtained in the general population of the same culture preferably serve as norm population (Fayers & Machin, 2007). Since only an Australian norm population is available and QoL ratings within the Dutch and Australian population are similar this comparison does provide insights into the QoL of life of the parents within our study population. The norm population scores are based on the general Australian population recruited through random telephone selection and weighted by socio-economic status (n = 396, 64% males, mean age of 48.2 years, s.d. = 17.3). Norm values are present for women and men [26]. The questionnaires were scored using a manual-based syntax in SPSS.

#### **Covariates**

Social demographic markers (marital status, education, financial situation, country of origin) are measured with a self-reported social-demographic questionnaire. The

questions were: (1) What is your marital status (single, cohabiting/married, (2) What is your level of completed education (primary education/lower pre-vocational education, secondary education/secondary vocational education, higher vocational education/academic education), (3) What is your income (below average/less than 2800 euros per month, average/around 2800 euros/month, above average/more than 2800 euros/month), (4) What is your country of birth.

Psychological distress is measured with the Brief Symptom Inventory (BSI; [10]). The BSI consists of 53 items and is the abbreviated version of the Symptom Checklist 90 (SCL-90). Within this study, the BSI total scale was used, which measures the severity of psychological distress. The reliability of the total BSI scale is good ( $\alpha$ =0.96, inter-item correlation=0.32, test-retest correlation=0.90), the validity is supported by good discriminatory power between patients and healthy respondents as well as between patients' groups with different diagnoses. Questions that are addressed within the BSI include: How much trouble did you have in the past week from: 'being quickly annoyed by something' or 'being anxious in open squares or large spaces' [5, 10]).

#### **Statistical Analysis**

Social demographic markers (marital status, education, financial situation, country of origin) and psychological distress (BSI) were compared to the general population using Pearson  $\chi^2$  test, to determine which variable should be included within analysis as covariates.

To evaluate parental stress weighted means and pooled standard deviations for the three parental stress areas (parental conflicting feelings, difficulties with parenting and role confinement) in the study population were calculated. Mothers raw scores from the study population were compared to mothers of the norm population using Welch's t-tests [11, 51]. The differences between mothers from the study population and the norm population on the three areas of the OBVL are determined by comparing the T-scores of the study population to the clinical cut-off T-scores scores provided by the OBVL manual, see "Appendix 1" [51]. Since no norm scores for fathers are available, raw scores on the OBVL of mothers from the study population are compared to raw scores of fathers from the study population using Welch's t-tests to explore whether there is a difference between mothers and fathers. To report on parental stress scores, z-scores were calculated based on mothers of typically developing children [1].

To explore the QoL outcomes in the four QoL domains of the WHOQoL-BREF (physical, psychological, social and environment) mothers and fathers within the study population are compared with women and men of the norm population [26] using Welch's *t*-tests. The differences between the



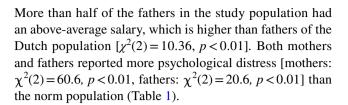
study population and the norm population are determined by comparing domain scores of the mothers and fathers of the study population with the women and men of the norm population [26]. Scores are considered clinically relevant when they are within the 'poor' category of the norm population ("Appendix 2").

To study the relation between parental stress areas and QoL domains linear regressions for both mothers and fathers were performed on raw scores of all variables. During step one the enter method was used wherein the covariates in which the study population significantly differed from the norm population were entered. In step two forward selection was used wherein the parental stress area that had the highest correlation with the parental QoL domain was entered first. By this model, we examined which of the parental stress areas were a significant additional predictor of parents' QoL when the covariates were corrected, regardless of whether they were significantly different. Correlations were performed between the raw scores of the OBVL and the WHOQoL-BREF raw scores. For all analyses, the statistical criterion for entry was a probability of p < 0.05. When no effect between the independent (parental stress) and dependent (QoL) variables was present, it was examined whether (1) there was an interaction effect, as one of the covariates could influence this relationship or (2) there was curvilinearity, as this type of relationship wherein the pattern of association between the dependent and independent variables change as the values of the variables change is not detected by linear regression analysis. Analyses were performed using Statistical Package for the Social Sciences (SPSS) version 25.0.

#### Results

#### **Descriptive Statistics**

A total of 184 families [children with their parent(s)] were eligible to participate in this study. Of these 184 families, 130 families allowed to be approached by the research team after being asked by their therapists. 70 families of these 130 indicated that they wanted to participate and signed informed consent. However, 9 of the 70 families decided before the start of the study that they could not participate because of lack of time. The included 61 families comprised out of 107 parents (mothers: n = 56, mean age = 34.44 years, s.d. = 4.69; fathers: n = 51, median age = 37.0 years, IQR = 6.0) of 61 children with ASD (mean age = 4.6 years, s.d. = 1.1, 55 boys). Within the current study population three times as few single fathers were present than in the norm population [ $\chi^2(1) = 7.33$ , p < 0.01]. Both mothers and fathers were higher educated than the Dutch general population [mothers:  $\chi^2(2) = 14.0$ , p < 0.001, fathers:  $\chi^2(2) = 7.23$ , p < 0.03].



#### **Parental Stress**

#### **Parental Conflicting Feelings**

Mothers of a young child with ASD experience more stress from conflicting feelings towards their child compared to mothers of typically developing children from the general population (t = -5.49, p < 0.01, z = 1.06, see Table 2). 51.8% Of the mothers' report (sub)clinical stress from conflicting feelings towards their child. Mothers and fathers do not differ in experienced stress from their conflicting feelings towards their child (t = 0.41, t = 0.18).

#### **Parenting Difficulties**

Mothers experience more stress deriving from difficulties with parenting than mothers of typically developing children (t=-7.93, p<0.01, z=1.09, see Table 2). 55.4% Of the mothers' experience (sub)clinical problems deriving from difficulties with parenting. Mothers and fathers display comparable parental stress from difficulties in parenting of their young child with ASD (t=-1.26, p=0.08).

#### **Role Confinement**

Mothers show more parental stress from feeling confined in their role as a parent compared to mothers of typically developing children (t = -8.55, p < 0.001, z = 1.04, see Table 2). 55.4% Of the mothers' experience (sub)clinical problems with role confinement. Mothers experience more stress in feeling confined in their role as a parent compared to fathers of a child with ASD (t = 3.25, p = < 0.01, Table 2).

#### **Quality of Life**

#### **Physical QoL**

Both mothers (t = 5.08, p < 0.01) and fathers (t = 6.70, p < 0.01) of a young child with ASD experience lower physical QoL compared to the norm population (see Table 3). 20.0% Of the mothers and 6.1% of the fathers experience poor physical QoL.



 Table 1
 Descriptives of the participating parents and their young children with ASD within this study compared to the Dutch population

			ASD parents vs. comparison group	$\chi^2$	p	Comparison group
	N	%	Expected %			
Marital status						
Mothers						
Single	10	19.2	23.0	0.42	NS	Dutch families (n=798,200) with children living at home < 18 year in 2022 [16] (https://www.nji.nl)
Living together/married	42	80.8	77.0			
Fathers						
Single	3	6.3	23.0	7.33	< 0.01	Dutch families (n = 798,200) with children living at home < 18 year in 2022 [16] (https://www.nji.nl)
Living together/married	44	93.6	77.0			
Education level						
Mothers						
Low	5	9.6	30.6	14.0	< 0.01	Dutch general population (n = 15,562,700) in 2020/2021 [8, 9] (https://opendata.cbs.nl)
Middle	23	44.2	41.7			
High	24	46.1	27.7			
Fathers						
Low	6	13.0	30.6	7.23	< 0.05	Dutch general population (n = 15,562,700) in 2020/2021 [8, 9] (https://opendata.cbs.nl)
Middle	22	47.8	41.7			
High	18	39.1	27.7			
Financial income						
Mothers						
Below average	24	51.1	47.4	0.41	NS	Dutch female population (n=684,940) in 2020 [8, 9] (https://www.cbs.nl)
Average	14	29.8	34.2			
Above average	9	19.1	18.4			
Fathers						
Below average	8	17.8	28.8	10.36	< 0.01	Dutch male population (n=633,830) in 2020 [8, 9] (https://www.cbs.nl)
Average	10	22.2	34.3			
Above average	27	60.0	36.7			
Psychological distress						
Mothers						
Normal	21	44.7	50.0	60.6	< 0.01	Standard population (n = 1206) from the BSI [5]
Sub-clinical	5	10.6	15.9			
Clinical	21	44.7	6.7			
Fathers						
Normal	29	65.9	50.0	20.6	< 0.01	Standard population (n = 1206) from the BSI [5]
Sub-clinical	2	4.5	15.9			
Clinical	13	29.5	6.7			
Country of origin						
Mothers						
Netherlands	42	79.2	73.8	0.51	NS	Total first- and second-generation immigrants (n=2,241,220) in the Dutch population in 2022 [7] (https://www.cbs.nl)
Non-Dutch-Western	6	11.3	11.5			
Non-Dutch Non-Western	5	9.4	14.7			
Fathers						



Table 1 (continued)

	Pare of c with ASI	hild 1	ASD parents vs. comparison group	$\chi^2$	p	Comparison group
	N	%	Expected %			
Netherlands	41	87.2	74.0	2.93	NS	Total first- and second-generation immigrants (n=2,241,220) in the Dutch population in 2022 [7] (https://www.cbs.nl)
Non-Dutch-Western	1	2.1	11.5			
Non-Dutch Non-Western	5	10.6	14.5			

<sup>%</sup> Percentage within the study or norm population, NS not significant

**Table 2** Parental stress in mothers of a young child with ASD compared to mothers of typically developing young children and fathers of a young child with ASD, measured with the parental stress questionnaire (OBVL)

Parental stress	Study population Mothers	Norm population Mothers	p	Study population Mothers	Study population Fathers	p
	(n = 56)	(n = 848)		(n = 56)	(n=51)	
	Mean (sd.)	Mean (sd.)		Mean (sd.)	Mean (sd.)	
Conflicting feelings	9.86 (3.27)	7.78 (2.17)	< 0.01	9.86 (3.27)	9.58 (3.85)	NS
Parenting difficulties	14.39 (3.61)	11.51 (2.94)	< 0.01	14.39 (3.61)	15.34 (4.64)	NS
Role confinement	13.50 (4.68)	9.53 (2.76)	< 0.01	13.50 (4.68)	10.93 (3.81)	< 0.01

The norm population including mothers of typically developing children is derived from the parental stress questionnaire (OBVL) manual [51]. To correct for the age difference between the study population (3 till 7 years) and norm population (0 to 3 years and 4 to 11 years), weighted means and pooled standard deviations are created for the norm population. The parental stress score for 'conflicting feelings' and 'role confinement' is min. 6 and max. 24. The parental stress score for 'parenting difficulties' is min. 7 and max. 24

Table 3 Quality of Life in parents of a young child with ASD compared to the norm population measured with the WHOQoL-BREF

Quality of life	Study population	Norm population	$p^{\mathrm{b}}$	Study population	Norm population	$p^{c}$
	Mothers	Women		Fathers	Man	
	n=55	n = 481		n=49	n = 376	
	Mean (sd.)	Mean (sd.)		Mean (sd.)	Mean (sd.)	
Physical QoL	56.99 (10.86)	72.1 (14.2)	< 0.01	63.80 (8.95)	75.8 (12.7)	< 0.01
Psychological QoL	58.95 (8.73)	69.1 (10.5)	< 0.01	61.69 (8.75)	70.3 (11.9)	< 0.01
Social QoL	57.31 (10.07)	70.9 (17.1)	< 0.01	55.18 (11.95)	69.8 (16.4)	< 0.01
Environmental QoL	61.94 (9.74)	74.6 (12.5)	< 0.01	63.06 (8.61)	75.4 (11.7)	< 0.01

<sup>&</sup>lt;sup>a</sup>The norm population included a general population derived from Hawthorne et al. [26], providing one decimal

#### **Psychological QoL**

Both mothers (t = 5.34, p < 0.01) and fathers (t = 5.10, p < 0.01) of a young child with ASD experience lower psychological QoL compared to the norm population (see Table 3). Of the mothers, 38.2% report a poor

psychological QoL. Of the fathers, 20.4% experience their psychological QoL as poor.

#### **Social QoL**

Both mothers (t = 5.04, p < 0.01) and fathers (t = 4.63, p = 0.01) report lower social QoL compared to the norm



<sup>&</sup>lt;sup>b</sup>Significant difference between mothers of the study population and females of the general population

<sup>&</sup>lt;sup>c</sup>Significant difference between fathers of the study population and males of the general population

population (see Table 3). Of the mothers, 63.6% report poor social QoL and so do 44.9% of the fathers.

#### **Environmental OoL**

Both mothers (t = 6.17, p < 0.01) and fathers (t = 7.56, p < 0.01) of a young child with ASD experience lower environmental QoL compared to the norm population (see Table 3). Of the mothers, 47.3% report poor environmental QoL and 65.3% of the fathers experience their environmental QoL as poor (Table 3).

#### **Associations of QoL by Specific Parental Stress Areas**

#### **Mothers Physical QoL**

During step one of the regression analysis the enter method was used wherein the covariates mother's education level and mothers' psychological distress were added. In step two forward selection was used wherein stress derived from feeling confined in their motherly role was entered first (r = -0.44, p < 0.01), followed by mothers' conflicting feelings towards her child (r = -0.29, p < 0.05). Results show that 31% of the variance in mothers physical QoL could be explained mothers' psychological distress [F(2,43) = 9.86, p = < 0.01]. Another 7% of variance in mothers' physical QoL could be explained by mothers' stress derived from feeling confined in their motherly role [F(1,42) = 5.02, p = 0.03]. The best fitting models were found for mothers' role confinement. Mother's conflicting feelings towards their child did not provide significant improved variance.

#### **Mothers Psychological QoL**

During step one of the regression analysis the enter method was used wherein the covariates: mothers' education level and mothers' psychological distress were added. In step two forward selection was used wherein mothers' conflicting feelings towards her child was entered first (r=-0.36, p<0.01), followed by feelings of confinement in their motherly role (r=-0.35, p<0.01). Results show that 23% of the variance in mothers psychological QoL could be explained by mothers' psychological distress [F(2,43)=6.53, p=<0.01]. Another 8% of variance in mothers psychological QoL could be explained by mothers' conflicting feelings towards their child [F(1,42)=7.76, p=0.04]. The best fitting models were found for mothers' conflicting feelings towards their child. Mothers' role confinement did not provide significant improved variance.

#### **Mothers Social QoL**

During step one of the regression analysis the enter method was used wherein the covariates: mothers education level and mothers' psychological distress were added. In step two forward selection was used wherein mothers' conflicting feelings towards her child was entered first (r = -0.36,p < 0.05), followed by feelings of confinement in their motherly role (r = -0.35, p < 0.01). Results show that 26% of the variance in mothers social QoL could be explained mothers' psychological distress and their education level [F(2,43) = 7.50, p = < 0.01]. Another 3% of variance in mothers psychological QoL could be explained by mothers' conflicting feelings towards their child [F(1,35)=4.31,p = < 0.01]. The best fitting models were found for mothers' psychological distress. Mothers' conflicting feelings and role confinement did not provide significant improved variance. No interaction effect or curvilinearity was present.

#### **Mothers Environmental OoL**

During step one of the regression analysis the enter method was used wherein the covariates: mothers education level and mothers' psychological distress were added. In step two forward selection was used wherein mothers' feelings of confinement in their motherly role (r = -0.34, p < 0.01) was entered. Results show that 36% of the variance in mothers environmental QoL could be explained mothers' psychological distress [F(2,43)=11.86, p = <0.01]. The best fitting models were found for mother's psychological distress. Mothers' role confinement did not provide significant improved variance. No interaction effect or curvilinearity was present (Table 4).

#### **Fathers QoL Associated with Paternal Stress Areas**

#### **Fathers Physical QoL**

During step one of the regression analysis the enter method was used wherein the covariates: fathers' marital status, education level, income and fathers' psychological distress were added. In step two forward selection was used wherein stress derived from difficulties with parenting was entered first (r=-0.44, p<0.01), followed by fathers' conflicting feelings towards her child (r=-0.37, p<0.01), and feelings of confinement in their fatherly role (r=-0.37, p<0.01). Results show that 49% of the variance in fathers physical QoL could be explained fathers' psychological distress [F(4,34)=8.15, p=<0.01]. Another 14% of variance in fathers physical QoL could be explained by fathers' conflicting feelings towards their child [F(1,33)=12.01, p=<0.01]. The best fitting models were found for fathers' conflicting feelings towards their child. Fathers' difficulties



**Table 4** Mothers of a young child with ASD stepwise regression analysis to identify associations of QoL domains measured with the WHOQoL-BREF by maternal stress areas measured with the OBVL

		R	$R^2$	Adju	sted R <sup>2</sup>			Change stat	istics				
						the est	imate	$R^2$ change	F chai	nge	df1	df2	Sig- nificant F change
Physical QoL													
Covariates		0.56	0.31	0.28		2.30		0.31	9.86		2	43	< 0.01
Covariates + role confine	ment	$0.62^{a}$	0.38	0.34		2.20		0.07	5.03		1	42	0.03
Psychological QoL													
Covariates		0.48	0.23	0.20		1.91		0.23	6.53		2	43	< 0.01
Covariates + conflicting f	feelings	$0.56^{b}$	0.31	0.26		1.83		0.08	4.76		1	42	0.04
Social QoL													
Covariates		0.51	0.26	0.22		2.25		0.26	7.50		2	43	< 0.01
Environmental QoL													
Covariates		$0.60^{a}$	0.36	0.33		2.02		0.36	11.86		2	43	< 0.01
	Unstan	dardized	coeffici	ents	Standar		t	Significa	nce	95.0%	Confi	dence	interval for B
	В	Sta	ndard ei	ror	β					Lowe	r bound	d	Upper bound
Physical QoL													
(Constant)	27.39	2.7	4				9.99	0.00		21.86			32.92
Education	-0.13	0.2	8		-0.05		-0.48	0.63		-0.7	1		0.43
Psychological distress	-0.18	0.0	4		-0.48		-3.92	0.00		-0.2	7		-0.08
Conflicting feelings	-0.16	0.0	7		-0.28		-2.24	0.03		-0.3	0		-0.01
Psychological QoL													
(Constant)	23.70	2.2	7				10.40	0.00		19.10			28.30
Education	0.01	0.2	5		0.00		0.06	0.94		-0.5	0		0.53
Psychological distress	-0.12	0.0	3		-0.41		-3.16	0.01		-0.2	0		-0.04
Conflicting feelings	-0.19	0.0	8		-0.31		-2.18	0.03		-0.3	7		-0.01
Social QoL													
(Constant)	24.18	2.7	7				8.70	0.01		18.58			29.79
Education	-0.60	0.2	8		-0.27		-2.12	0.03		-1.1	8		-0.03
Psychological distress	-0.14	0.0	4		-0.41		-3.13	0.01		-0.2	4		-0.05
Environmental QoL													
(Constant)	27.27	2.5	0				10.88	0.01		22.22			32.33
Education	-0.30	0.2	58		-0.14		-1.17	0.24		-0.8	2		0.21
Psychological distress	-0.19	0.0	42		-0.57		-4.66	0.01		-0.2	8		-0.11

In step one, the covariates: education level and psychological distress were entered as mothers differed significantly from the norm population on these variables. In step two the maternal stress areas were added in ascending order of correlation with QoL

with parenting and role confinement did not provide significant improved variance.

#### **Fathers Psychological QoL**

During step one of the regression analysis the enter method was used wherein the covariates: fathers' marital status, education level, income and fathers' psychological distress were added. In step two forward selection was used wherein stress derived from feeling confined in their fatherly role was entered first (r=-0.33, p<0.05), followed by fathers' conflicting feelings towards their child (r=-0.43, p<0.01), and difficulties with parenting (r=-0.43, p<0.01). Results show that 36% of the variance in fathers psychological QoL could be explained fathers' psychological distress [F(4,34)=4.68, p=<0.01]. Another 18% of variance in fathers psychological QoL could be explained by fathers' difficulties with parenting their child [F(1,33)=12.94,



<sup>&</sup>lt;sup>a</sup>Covariates + Role confinement and Conflicting feelings towards the child

<sup>&</sup>lt;sup>b</sup>Covariates + Conflicting feelings towards the child and Role confinement

p = <0.01]. The best fitting models were found for fathers' difficulties with parenting. Fathers' conflicting feelings and feelings of role confinement did not provide significant improved variance.

#### **Fathers Social QoL**

During step one of the regression analysis the enter method was used wherein the covariates: fathers' marital status, education level, income and fathers' psychological distress were added. In step two forward selection was used wherein stress derived from conflicting feelings towards their child was entered (r=-0.38, p<0.01). Results show that 55% of the variance in fathers social QoL could be explained fathers' psychological distress and their education level [F(4,34)=10.50, p=<0.01]. Another 10% of variance in fathers social QoL could be explained by fathers' conflicting feelings towards their child [F(1,33)=7.15, p=0.01]. The best fitting models were found for fathers' conflicting feelings.

#### **Fathers Environmental QoL**

During step one of the regression analysis the enter method was used wherein the covariates: fathers' marital status, education level, income and fathers' psychological distress were added. In step two forward selection was used wherein stress derived from fathers' difficulties with parenting was entered first (r = -0.40, p < 0.01), followed by fathers' conflicting feelings towards their child (r = -0.33, p < 0.05). Results show that 32% of the variance in fathers environmental QoL could be explained fathers own psychological distress [F(4,34) = 3.97, p = 0.01]. Another 8% of variance in fathers social QoL could be explained by fathers' difficulties with parenting [F(1,33) = 4.17, p = 0.04]. The best fitting models were found for fathers' difficulties with parenting (Table 5).

#### Discussion

This study shows that high parental stress is already present in early parenthood, in which mothers and fathers display a different pattern. Their stress is closely related with specific QoL domains when raising a young child with ASD.

The current study indicates that already in the early years of raising children with ASD, parents experience higher levels of parental stress compared to mothers of typically developing children. These results are consistent with the limited research, which is done with respect to parenting children with ASD at this young age [18, 19, 23]. What is new, is that our study shows that high maternal stress derives from conflicting feelings towards their child, from feelings and thoughts concerning the challenges and difficulties

encountered while parenting and from feeling confined in their general functioning due to their parenting role. While most studies focus on parental stress in general, our results provide specific insight into what parental stress stems from. Our results appear to be consistent with the increased parental stress resulting from unsatisfactory parent—child interactions and the child's behavior characteristics which make him/her easy of difficult to manage [23], different parental stress questionnaires were used. As the PSI-sf [23] is an international questionnaire and the OBVL has been specifically developed for the Dutch population [33, 51].

In addition, this study explored differences between fathers and mothers showing that they display comparable parental stress from conflicting feelings towards their child and from difficulties with parenting their young child with ASD. Mothers experience more stress due to their parenting role than fathers. With respect to previous studies including both mothers and fathers, limited research explored both their stress levels, the studies that did, found contrasting results [3, 21, 24, 38, 42, 47]). For instance, some studies show that mothers and fathers were found to have similar levels of stress [21, 24] and others display that mothers had higher levels of stress than fathers [21, 24, 47]. Also, maternal stress from personal burdens such as poor health/ mood, excessive time demands, or overprotection/dependency in comparison to fathers were identified [28, 38]. The contrasting results within these studies can be explained by the different age groups [21, 24, 38, 47], other instruments used PSI-4/SIPA [24], QRSFC [47] or QRS-S [38] or can be due to cultural differences (Western [24, 38] and Non-Western [47]). The difference in parental stress from feeling confined in their general functioning due to their parental role between mothers and fathers in this study can probably be explained by how mothers and fathers experience childcare. An important factor may be that Dutch mothers are often the primary caretaker of the child and will therefore be exposed to their child's needs and problems on a more frequent basis than the other caretaker [6, 16] (https://www.nji. nl). Nevertheless, this study shows that both parents experience increased parental stress levels already at a young age of their child. As a result, fathers potentially have the same health risks as mothers. However, a recent study by van der Lubbe et al. [49] shows that although fathers and mothers of a young child with ASD both experience high parental stress levels, only mothers show more obesity, abdominal obesity, and metabolic syndrome than the general population [49]. An explanation for this can be that fathers and mothers use different forms of stress coping as is shown by Hastings et al. [25] where mothers reported more frequent use of active avoidance and problem-focused coping strategies than fathers [25]. While it is becoming increasingly clear that not only mothers, but also fathers of young children with ASD also experience high parental stress, although study designs



**Table 5** Fathers of a young child with ASD stepwise regression analysis to identify associations of QoL domains measured with the WHOQoL-BREF by paternal stress areas measured with the OBVL

	R	$\mathbb{R}^2$	Adjust	ed R <sup>2</sup>	Standard		Change statistics					
					the estima	ate	R <sup>2</sup> change	F cha	nge	df1	df2	Significan F change
Physical QoL												
Covariates	0.7	0.49	0.43		1.66		0.49	8.15		4	34	< 0.01
Covariates + conflicting feelings	0.79	9 <sup>a</sup> 0.63	0.57		1.44		0.14	12.01		1	33	< 0.01
Psychological QoL												
Covariates	0.6	0.36	0.28		1.96		0.36	4.68		4	34	< 0.01
Covariates + difficulties parenting	0.7	3 <sup>b</sup> 0.54	0.47		1.69		0.18	12.94		1	33	< 0.01
Social QoL												
Covariates	0.7	4 0.55	0.50		2.31		0.55	10.51		4	34	< 0.01
Covariates + conflicting feelings	0.8	0° 0.63	0.58		2.13		0.08	7.15		1	33	< 0.05
Environment QoL												
Covariates	0.5	6 0.32	0.24		1.98		0.32	3.97		4	34	< 0.05
Covariates + difficulties parenting	0.6	3 <sup>d</sup> 0.40	0.30		1.90		0.08	4.17		1	33	< 0.05
	Unstandar	dized coeffici	ents		ardized	t	Significan	ce	95.0%	Confide	ence inte	erval for B
	В	Standard e	error	coeffic β	cients				Lowe	r Bound	1	Upper Bound
Physical QoL												
(Constant)	18.01	1.24				14.55	0.00		15.54		2	20.59
Marital status	0.14	0.19		0.08		0.70	0.49		-0.2	6	(	).53
Education	0.23	0.37		0.07		0.61	0.54		-0.5	3	(	).98
I ncome	0.00	0.00		-0.04	ļ	-0.39	0.70		-0.0			0.00
Psychological distress	-2.08	0.42		-0.58	3	-4.99	0.00		-2.9	2		-1.23
Conflicting feelings	-0.25	0.07		-0.40	)	-3.47	0.00		-0.39	9		-0.10
Psychological QoL												
(Constant)	19.84	1.78				11.15	0.00		16.22		2	23.47
Marital status	0.12	0.22		0.07		0.53	0.60		-0.3	4	(	0.57
Education	-0.05	0.44		-0.01		-0.18	0.92		-0.9	5	(	0.86
Income	0.00	0.00		0.07		0.56	0.58		-0.0	0	(	0.00
Psychological distress	-1.66	0.48		-0.44	ļ	-3.47	0.00		-2.6	4		-0.69
Difficulties with parenting	-0.26	0.07		-0.46	ó	-3.60	0.00		-0.40	0		-0.11
Social QoL												
(Constant)	13.90	1.83				7.59	0.00		10.17			17.63
Marital status	0.33	0.29		0.14		1.13	0.27		-0.2	6	(	).91
Education	1.22	0.55		0.26		2.24	0.03		0.11		2	2.34
Income	0.00	0.00		0.08		0.72	0.48		-0.0	0	(	0.00
Psychological distress	-2.74	0.61		-0.51		-4.47	0.00		-3.9			-1.49
Conflicting feelings	-0.28	0.10		-0.30	)	-2.67	0.01		-0.49	9		-0.07
Environment QoL												
(Constant)	17.59	2.00				8.79	0.00		13.52		2	21.66
Marital status	0.04	0.25		0.02		0.16	0.87		$-0.4^{\circ}$		(	).55
Education	0.54	0.50		0.16		1.08	0.29		-0.4	8		1.56
Income	0.00	0.00		0.21		1.45	0.16		-0.0	0	(	0.01
Psychological distress	-1.20	0.54		-0.32	2	-2.23	0.03		-2.3	0		-0.10
Difficulties with parenting	-0.16	0.08		-0.30		-2.04	0.05		-0.3			-0.00

In step one, the covariates: psychological distress, education, income, and marital status were entered as fathers differed significantly from the norm population on these variables. In step two the paternal stress areas were added in ascending order of correlation with QoL

<sup>&</sup>lt;sup>d</sup>Covariates + Difficulties with parenting and conflicting feelings towards the child



<sup>&</sup>lt;sup>a</sup>Covariates + Parenting difficulties, conflicting feelings towards the child

<sup>&</sup>lt;sup>b</sup>Covariates + Role confinement, conflicting feelings towards the child and Difficulties with parenting

<sup>&</sup>lt;sup>c</sup>Covariates + conflicting feelings towards the child

did not always point to this comparison [3, 21, 24, 38, 42, 47]). In addition, the insight is emerging that fathers cope with their paternal stress differently than mothers [25] and this study points to the relation with their physical QoL. Research into their physical status including complaints of pain and health care use is needed to gain insight what risks these pose to fathers and how this can be addressed within the treatment of families with a child with ASD.

This study also explored the QoL in parents of young children with ASD. Our results show that parents experience lower QoL with respect to their psychological- and physical well-being, their social relationships and satisfaction with their living situation and other social economic factors compared to the general population. In addition, differences between mothers and fathers QoL were explored, showing that both mothers and fathers experience a lower QoL on all the QoL domains compared to the general population. These results are in line with an earlier study by Pisula & Porebowicz-Dorsmann (2017) comparing both mothers and fathers of older school aged children with ASD, showing that they both experience a lower satisfaction with their psychological- and physical well-being and social relationships than parents of typically developing children [38]. This study adds to our knowledge that the experience of low parental OoL already starts during the early years of parenting a child with ASD and that during this age also living situation and other social economic factors are important aspects of parental QoL. Looking at the relationship between parental stress and QoL, it appears that the extent to which mothers feel they are not being able to take care of themselves due to their role as a mother is related to how they perceive their physical health. While mothers' conflicting feelings towards their child associate with their psychological wellbeing. This is different for fathers; fathers' conflicting feelings towards their child relate to how satisfied they are with their physical health and social life, while fathers' difficulties with parenting are related to how satisfied they are with their living conditions. Thus, with respect to QoL, a -gender specific tendency seems to be present between maternal or paternal stress areas and their QoL domains. This could be an explanation why the effect of play-based interventions, which are often used in young children with ASD, on general parental stress is therefore variable [15]. As play-based interventions in children with ASD focus on parental stress in general, rather than on specific parental stress areas. This could argue in favour of looking at the stress levels of parents in different areas of functioning, for both mothers and fathers separately, before starting treatment.

#### Strengths

Studies on parental stress in young children with ASD are underrepresented as most studies on parental stress and QoL include parents of children above the age of 7 years. Additionally, fathers are included in contrast to most studies on parental stress and QoL including only mothers.

#### Limitations

The current study used a cross-sectional design, thus changes over time could not be observed. As the current study is part of on an ongoing RCT, we will provide these data in the future. Although the comparison of two populations with different cultural backgrounds (Dutch and Australian) is suboptimal and should be discussed in relation to interpretation of results, we conclude that given the similarities in government systems, cultural diversity, QoL ratings, and previous literature on the comparison of both populations, this comparison provides good insights into the QoL of the Dutch parents within our study population [37, 44]. Additionally, the mean age of children in this study is 4.6 years, however the age at which the diagnoses of ASD were received is unknown. This is a critical factor in interpreting parental stress, as research has shown that delays in diagnosis increase parental stress [35, 54]. The average age at which ASD is diagnosed in Dutch children < 18 is at 5.1 years old, almost equal to the average worldwide age of 5 years [4, 50]. Therefor the majority of the children and their parents in this study in all probability did not experience delays in diagnosis.

In conclusion, already at young age, parenting of children with ASD is a major challenge for both mothers and fathers, resulting in high stress levels and compromised QoL. Based on our findings we recommend that attention is given to physical, psychological, and social well-being of parents in the treatment of children with ASD. By doing so, both parents and child get the attention to optimally support the child's development.

#### **Summary**

Parents of children with ASD are at risk for chronic stress due to challenging parenting. It is unknown whether stress is already present in early parenthood, similar for mothers and fathers and if this impacts quality of life (QoL). The present study explored whether high parental stress and low QoL was already present in both mothers (n=56) and fathers (n=51) of young children (aged 3 to 7) with ASD and if maternal and paternal stress impacted parental QoL. Associations between parental stress and QoL were examined by questionnaires: the parenting burden questionnaire (in Dutch: *Opvoedbelasting Vragenlijst*) and the World Health Organization Quality of Life (abridged version) questionnaire. This study showed that high parental stress from conflicting feelings towards their child and from difficulties with



parenting was already present in early parenthood. Mothers and fathers displayed a different pattern, where mothers experience more stress due to their parenting role than fathers. This observation might be explained by how mothers and fathers experience childcare and that Dutch mothers are often the primary caretaker of their child with ASD, and will therefore be exposed to their child's needs and problems on a more frequent basis than fathers. Also, the experience of low QoL already started during the early years of parenting a child with ASD as both fathers and mothers of young children with ASD reported lower QoL with respect to their psychological- and physical well-being, their social relationships and satisfaction with their living situation and other social economic factors compared to the general population. Their parentings stress was closely related with specific QoL domains in which also a gender specific tendency was present between maternal or paternal stress areas and their QoL domains. Increased maternal conflicting feelings towards the child associated with lower psychological OoL, while high maternal feelings of role confinement associated with low physical QoL. Increased paternal conflicting feelings towards their child related to lower physical and social QoL, while fathers with more parenting difficulties reported less satisfaction with their psychological and environmental wellbeing. Thus, already at young age, parenting children with ASD is a major challenge for both mothers and fathers. Our study argues in favour of examining stress levels of parents in different areas of functioning, for both mothers and fathers separately, before starting treatment. Additionally, attention has to be given to physical, psychological, and social well-being of parents in the treatment of children with ASD. By doing so, both parents and child get the attention to optimally support the their child's development.

### Appendix 1: Interpretation Framework for the Parental Stress Questionnaire (OBVL)

T-scores	Percentile	Label	Meaning	Implication
<60	< 84	Normal range	No prob- lems	No consider- able worries
60–63	85–90	Subclinical range	Mild prob- lems	Problems deserve attention
64–66	91–95	Clinical range	Consider- able problems	Problems deserve treatment
67–69	96–97		Severe problems	
>70	>98		Very severe problems	

This interpretation framework is derived from the parental stress questionnaire (OBVL) manual [51]

# Appendix 2: Interpretation Framework for Parental Quality of Life Measured with the WHOQoL-BREF

	n	Health status	Physi	ical	Psycl	nologica	lSocia	ıl	Envi	
			Mear	ı (sd.)	Mear	ı (sd.)	Mear	n (sd.)	Mear	n (sd.)
Women	481	Excel- lent	89.0	(9.2)	82.0	(9.3)	82.0	(13.5)	83.9	(11.1)
		Very good	82.1	(11.7)	74.5	(11.4)	75.8	(16.6)	77.6	(12.0)
		Good	72.1	(14.2)	69.1	(10.5)	70.9	(17.1)	74.6	(12.5)
		Fair	61.8	(14.7)	64.4	(13.7)	71.3	(17.4)	70.5	(12.7)
		Poor	45.7	(18.6)	56.2	(13.6)	61.3	(21.4)	63.1	(12.9)
Men	376	Excel- lent	93.7	(7.7)	86.9	(11.8)	81.3	(15.5)	83.8	(11.1)
		Very good	83.3	(12.3)	76.0	(11.2)	72.9	(17.0)	79.5	(10.4)
		Good	75.8	(12.7)	70.3	(11.9)	69.8	(16.4)	75.4	(11.7)
		Fair	60.7	(15.3)	63.2	(12.1)	61.5	(20.9)	67.8	(12.6)
		Poor	46.2	(19.9)	55.5	(17.9)	57.4	(21.1)	67.4	(13.0)

This interpretation framework is derived from an Australian norm population [26]



#### **Appendix 3: Table of Standard Normal Probabilities for Z-Scores**

Table of Standard Normal Probabilities for Negative Z-scores



2	0.00	0.01	0.02	0.03	0.04	0.05	0.06	0.07	80.0	0.09
-3.4	0.0003	0.0003	0.0003	0.0003	0.0003	0.0003	0.0003	0.0003	0.0003	0.0002
-3.3	0.0005	0.0005	0.0005	0.0004	0.0004	0.0004	0.0004	0.0004	0.0004	0.0003
-3.2	0.0007	0.0007	0.0006	0.0006	0.0006	0.0006	0.0006	0.0005	0.0005	0.0005
-3.1	0.0010	0.0009	0.0009	0.0009	0.0008	0.0008	0.0008	0.0008	0.0007	0.0007
-3.0	0.0013	0.0013	0.0013	0.0012	0.0012	0.0011	0.0011	0.0011	0.0010	0.0010
-2.9	0.0019	0.0018	0.0018	0.0017	0.0016	0.0016	0.0015	0.0015	0.0014	0.0014
-2.8	0.0026	0.0025	0.0024	0.0023	0.0023	0.0022	0.0021	0.0021	0.0020	0.0019
-2.7	0.0035	0.0034	0.0033	0.0032	0.0031	0.0030	0.0029	0.0028	0.0027	0.0026
-2.6	0.0047	0.0045	0.0044	0.0043	0.0041	0.0040	0.0039	0.0038	0.0037	0.0036
-2.5	0.0062	0.0060	0.0059	0.0057	0.0055	0.0054	0.0052	0.0051	0.0049	0.0048
-2.4	0.0082	0.0080	0.0078	0.0075	0.0073	0.0071	0.0069	0.0068	0.0066	0.0064
-2.3	0.0107	0.0104	0.0102	0.0099	0.0096	0.0094	0.0091	0.0089	0.0087	0.0084
-2.2	0.0139	0.0136	0.0132	0.0129	0.0125	0.0122	0.0119	0.0116	0.0113	0.0110
-2.1	0.0179	0.0174	0.0170	0.0166	0.0162	0.0158	0.0154	0.0150	0.0146	0.0143
-2.0	0.0228	0.0222	0.0217	0.0212	0.0207	0.0202	0.0197	0.0192	0.0188	0.0183
-1.9	0.0287	0.0281	0.0274	0.0268	0.0262	0.0256	0.0250	0.0244	0.0239	0.0233
-1.8	0.0359	0.0351	0.0344	0.0336	0.0329	0.0322	0.0314	0.0307	0.0301	0.0294
-1.7	0.0446	0.0436	0.0427	0.0418	0.0409	0.0401	0.0392	0.0384	0.0375	0.0367
-1.6	0.0548	0.0537	0.0526	0.0516	0.0505	0.0495	0.0485	0.0475	0.0465	0.0455
-1.5	0.0668	0.0655	0.0643	0.0630	0.0618	0.0606	0.0594	0.0582	0.0571	0.0559
-1.4	0.0808	0.0793	0.0778	0.0764	0.0749	0.0735	0.0721	0.0708	0.0694	0.0681
-1.3	0.0968	0.0951	0.0934	0.0918	0.0901	0.0885	0.0869	0.0853	0.0838	0.0823
-1.2	0.1151	0.1131	0.1112	0.1093	0.1075	0.1056	0.1038	0.1020	0.1003	0.0985
-1.1	0.1357	0.1335	0.1314	0.1292	0.1271	0.1251	0.1230	0.1210	0.1190	0.1170
-1.0	0.1587	0.1562	0.1539	0.1515	0.1492	0.1469	0.1446	0.1423	0.1401	0.1379
-0.9	0.1841	0.1814	0.1788	0.1762	0.1736	0.1711	0.1685	0.1660	0.1635	0.1611
-0.8	0.2119	0.2090	0.2061	0.2033	0.2005	0.1977	0.1949	0.1922	0.1894	0.1867
-0.7	0.2420	0.2389	0.2358	0.2327	0.2296	0.2266	0.2236	0.2206	0.2177	0.2148
-0.6	0.2743	0.2709	0.2676	0.2643	0.2611	0.2578	0.2546	0.2514	0.2483	0.2451
-0.5	0.3085	0.3050	0.3015	0.2981	0.2946	0.2912	0.2877	0.2843	0.2810	0.2776
-0.4	0.3446	0.3409	0.3372	0.3336	0.3300	0.3264	0.3228	0.3192	0.3156	0.3121
-0.3	0.3821	0.3783	0.3745	0.3707	0.3669	0.3632	0.3594	0.3557	0.3520	0.3483
-0.2	0.4207	0.4168	0.4129	0.4090	0.4052	0.4013	0.3974	0.3936	0.3897	0.3859
-0.1	0.4602	0.4562	0.4522	0.4483	0.4443	0.4404	0.4364	0.4325	0.4286	0.4247
-0.0	0.5000	0.4960	0.4920	0.4880	0.4840	0.4801	0.4761	0.4721	0.4681	0.4641

Table of Standard Normal Probabilities for Positive Z-scores



z	0.00	0.01	0.02	0.03	0.04	0.05	0.06	0.07	0.08	0.09
0.0	0.5000	0.5040	0.5080	0.5120	0.5160	0.5199	0.5239	0.5279	0.5319	0.5359
0.1	0.5398	0.5438	0.5478	0.5517	0.5557	0.5596	0.5636	0.5675	0.5714	0.5753
0.2	0.5793	0.5832	0.5871	0.5910	0.5948	0.5987	0.6026	0.6064	0.6103	0.6141
0.3	0.6179	0.6217	0.6255	0.6293	0.6331	0.6368	0.6406	0.6443	0.6480	0.6517
0.4	0.6554	0.6591	0.6628	0.6664	0.6700	0.6736	0.6772	0.6808	0.6844	0.6879
0.5	0.6915	0.6950	0.6985	0.7019	0.7054	0.7088	0.7123	0.7157	0.7190	0.7224
0.6	0.7257	0.7291	0.7324	0.7357	0.7389	0.7422	0.7454	0.7486	0.7517	0.7549
0.7	0.7580	0.7611	0.7642	0.7673	0.7704	0.7734	0.7764	0.7794	0.7823	0.7852
0.8	0.7881	0.7910	0.7939	0.7967	0.7995	0.8023	0.8051	0.8078	0.8106	0.8133
0.9	0.8159	0.8186	0.8212	0.8238	0.8264	0.8289	0.8315	0.8340	0.8365	0.8389
1.0	0.8413	0.8438	0.8461	0.8485	0.8508	0.8531	0.8554	0.8577	0.8599	0.8621
1.1	0.8643	0.8665	0.8686	0.8708	0.8729	0.8749	0.8770	0.8790	0.8810	0.8830
1.2	0.8849	0.8869	0.8888	0.8907	0.8925	0.8944	0.8962	0.8980	0.8997	0.9015
1.3	0.9032	0.9049	0.9066	0.9082	0.9099	0.9115	0.9131	0.9147	0.9162	0.9177
1.4	0.9192	0.9207	0.9222	0.9236	0.9251	0.9265	0.9279	0.9292	0.9306	0.9319
1.5	0.9332	0.9345	0.9357	0.9370	0.9382	0.9394	0.9406	0.9418	0.9429	0.9441
1.6	0.9452	0.9463	0.9474	0.9484	0.9495	0.9505	0.9515	0.9525	0.9535	0.9545
1.7	0.9554	0.9564	0.9573	0.9582	0.9591	0.9599	0.9608	0.9616	0.9625	0.9633
1.8	0.9641	0.9649	0.9656	0.9664	0.9671	0.9678	0.9686	0.9693	0.9699	0.9706
1.9	0.9713	0.9719	0.9726	0.9732	0.9738	0.9744	0.9750	0.9756	0.9761	0.9767
2.0	0.9772	0.9778	0.9783	0.9788	0.9793	0.9798	0.9803	0.9808	0.9812	0.9817
2.1	0.9821	0.9826	0.9830	0.9834	0.9838	0.9842	0.9846	0.9850	0.9854	0.9857
2.2	0.9861	0.9864	0.9868	0.9871	0.9875	0.9878	0.9881	0.9884	0.9887	0.9890
2.3	0.9893	0.9896	0.9898	0.9901	0.9904	0.9906	0.9909	0.9911	0.9913	0.9916
2.4	0.9918	0.9920	0.9922	0.9925	0.9927	0.9929	0.9931	0.9932	0.9934	0.9936
2.5	0.9938	0.9940	0.9941	0.9943	0.9945	0.9946	0.9948	0.9949	0.9951	0.9952
2.6	0.9953	0.9955	0.9956	0.9957	0.9959	0.9960	0.9961	0.9962	0.9963	0.9964
2.7	0.9965	0.9966	0.9967	0.9968	0.9969	0.9970	0.9971	0.9972	0.9973	0.9974
2.8	0.9974	0.9975	0.9976	0.9977	0.9977	0.9978	0.9979	0.9979	0.9980	0.9981
2.9	0.9981	0.9982	0.9982	0.9983	0.9984	0.9984	0.9985	0.9985	0.9986	0.9986
3.0	0.9987	0.9987	0.9987	0.9988	0.9988	0.9989	0.9989	0.9989	0.9990	0.9990
3.1	0.9990	0.9991	0.9991	0.9991	0.9992	0.9992	0.9992	0.9992	0.9993	0.9993
3.2	0.9993	0.9993	0.9994	0.9994	0.9994	0.9994	0.9994	0.9995	0.9995	0.9991
3.3	0.9995	0.9995	0.9995	0.9996	0.9996	0.9996	0.9996	0.9996	0.9996	0.9997
3.4	0.9997	0.9997	0.9997	0.9997	0.9997	0.9997	0.9997	0.9997	0.9997	0.9998

Author Contributions All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Leanne Dijkstra-de Neijs and Daphne B. Boeke. The first draft of the manuscript was written by Leanne Dijkstra-de Neijs, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

**Funding** Funding was granted by the Korczak Foundation for Autism and Related Disorders and Foundation VCVGZ. We are very grateful for participation of the families of children with ASD in the Tandem study.

Data Availability Not applicable.

#### **Declarations**

Conflict of interest All authors declare that they have no conflicts of interest.

**Ethical Approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Institutional Review Board of Leiden University Medical Center, The Netherlands (NL6378.058.18, Dutch trial register: NL7534).

**Open Access** This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated

otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/.

#### References

- Allen MJ, Yen WN (2001) Introduction to measurement theory. Waveland Press, Long Grove
- Altiere MJ, Von Kluge ÆS (2009) Family functioning and coping behaviors in parents of children with autism. J Child Fam Stud 18(1):83–92. https://doi.org/10.1007/s10826-008-9209-y
- Baker-Ericzen MJ, Brookman-Frazee L, Stahmer A (2005) Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. Res Pract Pers Severe Disabil 30(4):194–204
- Begeer S, Wierda M, Venderbosch S (n.d.) NVA enquête 2013. www.autisme.nl
- Beurs EDE, Zitman FG (2006) De Brief Symptom Inventory (BSI)\*, de betrouwbaarheid en validiteit van een handzaam alternatief voor de SCL-90\*. Maandblad Geestelijke Volksgezondheid 61:120–141
- Centraal Bureau voor de Statistiek (2020) Huishoudens; kindertal, leeftijdsklasse kind, regio, 1 januari. Centraal Bureau voor de Statistiek. https://opendata.cbs.nl/statline/#/CBS/nl/dataset/71487 NED/table?fromstatweb
- Central Bureau for Statistics (https://www.cbs.nl) (n.d.) Residents with an origin outside the Netherlands. Central Bureau for Statistics. https://www.cbs.nl/nl-nl/dossier/dossier-asiel-migra



- tie-en-integratie/hoeveel-mensen-met-een-migratieachtergrondwonen-in-nederland-. Accessed 10 Nov 2022
- Central Bureau for Statistics Netherlands (https://opendata.cbs. nl) (n.d.) Graduates and graduates; type of education, from 1900. Central Bureau for Statistics Netherlands. https://opendata.cbs. nl/statline/#/CBS/nl/dataset/80384ned/table?ts=1668075923005. Accessed 10 Nov 2022
- Central Bureau for Statistics Netherlands (https://www.cbs.nl) (n.d.) Income of persons; income classes, personal characteristics. Central Bureau for Statistics Netherlands. https://opendata.cbs.nl/ statline/#/CBS/nl/dataset/83931NED/table?ts=1668000364049. Accessed 10 Nov 2022
- 10. De Beurs E (2008) Brief symptom inventory. PITS B.V., Leiden
- Delacre M, Lakens D, Leys C (2017) Why psychologists should by default use Welch's t-Test instead of Student's t-Test. Int Rev Soc Psychol 30(1):92–101. https://doi.org/10.5334/irsp.82
- DesChamps TD, Ibañez LV, Edmunds SR, Dick CC, Stone WL (2020) Parenting stress in caregivers of young children with ASD concerns prior to a formal diagnosis. Autism Res 13(1):82–92. https://doi.org/10.1002/aur.2213
- Dey M, Paz Castro R, Haug S, Schaub MP (2019) Quality of life of parents of mentally-ill children: a systematic review and metaanalysis. Epidemiol Psychiatr Sci 28(5):563–577. https://doi.org/ 10.1017/S2045796018000409
- Dijkstra-de Neijs L, Leenen PJM, Hays JP, Valk ES, Kraaij R, Rossum EFC, Ester WA (2020) Biological consequences of psychological distress in caregivers of children with autism spectrum disorder and its potential relevance to other chronic diseases including cancer. Curr Epidemiol Rep 7:139–148. https://doi.org/ 10.1007/s40471-020-00237-2
- Dijkstra-de Neijs L, Tisseur C, Kluwen LA, van Berckelaer-Onnes IA, Swaab H, Ester WA (2021) Effectivity of play-based interventions in children with autism spectrum disorder and their parents: a systematic review. J Autism Dev Disord. https://doi.org/10.1007/ s10803-021-05357-2
- Dutch Youth Institute (https://www.nji.nl) (n.d.) Figures on families. Dutch Youth Institute. https://www.nji.nl/cijfers/gezinnen. Accessed 10 Nov 2022
- Eisenhower AS, Baker BL, Blacher J (2005) Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. J Intellect Disabil Res 49(9):657– 671. https://doi.org/10.1111/J.1365-2788.2005.00699.X
- Enea V, Rusu DM (2020) Raising a child with autism spectrum disorder: a systematic review of the literature investigating parenting stress. J Ment Health Res Intellect Disabil 13(4):283–321. https://doi.org/10.1080/19315864.2020.1822962
- Estes A, Munson J, Dawson G, Koehler E, Zhou XH, Abbott R (2009) Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism 13(4):375–387. https://doi.org/10.1177/1362361309105658
- Fairthorne J, Hammond G, Bourke J, Jacoby P, Leonard H (2014)
   Early mortality and primary causes of death in mothers of children
   with intellectual disability or autism spectrum disorder: a retro spective cohort study. PLoS ONE 9(12):1–15. https://doi.org/10.
   1371/journal.pone.0113430
- Flippin M, Crais ER (2011) The need for more effective father involvement in early autism intervention: a systematic review and recommendations father communication coaching view project early development project view project. J Early Interv. https://doi. org/10.1177/1053815111400415
- George C, Herman KC, Ostrander R (2006) The family environment and developmental psychopathology: the unique and interactive effects of depression, attention, and conduct problems. Child

- Psychiatry Hum Dev 37(2):163–177. https://doi.org/10.1007/s10578-006-0026-5
- Giovagnoli G, Postorino V, Fatta LM, Sanges V, De Peppo L, Vassena L, De Rose P, Vicari S, Mazzone L (2015) Behavioral and emotional profile and parental stress in preschool children with autism spectrum disorder. Res Dev Disabil 45–46:411–421. https://doi.org/10.1016/j.ridd.2015.08.006
- Grebe SC, Mire SS, Kim H, Keller-Margulis MA (2021) Comparing fathers' and mothers' perspectives about their child's autism spectrum disorder. J Autism Dev Disord. https://doi.org/10.1007/S10803-021-05077-7
- Hastings RP, Kovshoff H, Brown T, Ward NJ, Espinosa FD, Remington B (2005) Coping strategies in mothers and fathers of preschool and school-age children with autism. Autism 9(4):377– 391. https://doi.org/10.1177/1362361305056078
- Hawthorne G, Herrman H, Murphy B (2006) Interpreting the WHOQoL-BRÈF: preliminary population norms and effect sizes. Soc Indic Res 77(1):37–59. https://doi.org/10.1007/ s11205-005-5552-1
- Hayes SA, Watson SL (2013) 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. J Autism Dev Disord 43(3):629–642. https://doi.org/10. 1007/s10803-012-1604-y
- Holroyd J (1988) A review of criterion validation research on the questionnaire on resources and stress for families with chronically ill or handicapped members. J Clin Psychol 44(3):335–354. https://doi.org/10.1002/1097-4679(198805)44:3%3c335::AID-JCLP2270440306%3e3.0.CO:2-T
- Hsiao YJ (2016) Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbor support. Res Autism Spectr Disord 23:122–130. https:// doi.org/10.1016/J.RASD.2015.10.008
- Hsiao YJ (2018) Autism spectrum disorders: family demographics, parental stress, and family quality of life. J Policy Pract Intellect Disabil 15(1):70–79. https://doi.org/10.1111/JPPI.12232
- Hsiao YJ, Higgins K, Pierce T, Whitby PJS, Tandy RD (2017) Parental stress, family quality of life, and family–teacher partnerships: families of children with autism spectrum disorder. Res Dev Disabil 70:152–162. https://doi.org/10.1016/J.RIDD.2017.08.013
- Karst JS, van Hecke AV (2012) Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. Clin Child Fam Psychol Rev 15(3):247–277. https:// doi.org/10.1007/s10567-012-0119-6
- Lee SJ, Gopalan G, Harrington D (2016) Validation of the parenting stress index-short form with minority caregivers. Res Soc Work Pract 26(4):429–440. https://doi.org/10.1177/1049731514 554854
- Marsack CN, Perry TE (2018) Aging in place in every community: social exclusion experiences of parents of adult children with autism spectrum disorder. Res Aging 40(6):535–557. https://doi.org/10.1177/0164027517717044
- Midence K (1999) The experience of parents in the diagnosis of autism: a pilot study. Autism. https://doi.org/10.1177/1362361399 003003005
- Netherlands Trial Register. (n.d.). Trial NL7534. Netherlands Trial Register. https://www.trialregister.nl/trial/7534. Accessed 27 Nov 2020
- Organization for Economic Cooperation and Development (2023)
   OECD. https://www.oecdbetterlifeindex.org/
- Pisula E, Porębowicz-Dörsmann A (2017) Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. PLoS ONE. https://doi.org/10.1371/journal.pone.0186536



- Rao PA, Beidel DC (2009) The impact of children with highfunctioning autism on parental stress, sibling adjustment, and family functioning. Behav Modif 33(4):437–451. https://doi.org/ 10.1177/0145445509336427
- Rezendes DL, Scarpa A (2011) Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: the roles of parenting stress and parenting self-efficacy. Autism Res Treat 2011:1–10. https://doi.org/10. 1155/2011/395190
- Riahi F, Izadi-Mazidi S (2012) Comparison between the mental health of mothers of children with autism and control group. Iran J Psychiatry Behav Sci 6(2):91–95
- Rivard M, Terroux A, Parent-Boursier C, Mercier C (2014) Determinants of stress in parents of children with autism spectrum disorders. J Autism Dev Disord 44(7):1609–1620. https://doi.org/10.1007/s10803-013-2028-z
- Seymour M, Allen S, Giallo R, Wood CE (2022) 'Dads kind of get forgotten': the mental health support needs of fathers raising a child with Autism Spectrum Disorder. J Fam Stud. https://doi. org/10.1080/13229400.2020.1809491
- 44. Skevington SM, Lotfy M, O'Connell KA (2004) The World Health Organization's WHOQoL-BREF quality of life assessment: psychometric properties and results of the international field trial a Report from the WHOQoL Group. Qual Life Res 13(2):299–310. https://doi.org/10.1023/B:QURE.0000018486. 91360.00
- 45. Smith LE, Greenberg JS, Mailick MR (2014) The family context of autism spectrum disorders: influence on the behavioral phenotype and quality of life. Child Adolesc Psychiatr Clin N Am 23(1):143–155. https://doi.org/10.1016/j.chc.2013.08.006
- Smith LE, Seltzer MM, Greenberg JS (2012) Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. J Autism Dev Disord 42(9):1836–1846. https://doi.org/10.1007/s10803-011-1422-7
- Soltanifar A, Akbarzadeh F, Moharreri F, Soltanifar A, Ebrahimi A, Mokhber N, Minoocherhr A, Shojut S, Naqvi A (2015) Comparison of parental stress among mothers and fathers of children with autistic spectrum disorder in Iran. Iran J Nurs Midwifery Res 20(1):93–98
- Trompenaars FJ, Masthoff ED, Van Heck GL, Hodiamont PP, De Vries J (2005) Content validity, construct validity, and reliability of the WHOQoL-BREF in a population of Dutch adult psychiatric outpatients. Qual Life Res 14(1):151–160. https://doi.org/10.1007/ s11136-004-0787-x
- van der Lubbe A, Swaab H, Vermeiren RRJM, Ester WA (2022) Stress, eating behavior and adverse health in parents of young children with autism spectrum disorder. J Autism Dev Disord. https://doi.org/10.1007/S10803-022-05825-3

- Van't Hof M, Tisseur C, van Berckelear-Onnes I, van Nieuwenhuyzen A, Daniels AM, Deen M, Hoek HW, Ester WA (2021) Age at autism spectrum disorder diagnosis: a systematic review and meta-analysis from 2012 to 2019. Autism 25(4):862–873. https://doi.org/10.1177/1362361320971107
- Vermulst A, Kroes G, De Meyer R, Nguyen L, Veerman JW (2015) Handleiding OBVL. https://www.praktikon.nl/resources/ vragenlijsten/handleiding\_obvl\_2015\_\_1\_.pdf
- Voliovitch Y, Leventhal JM, Fenick AM, Gupta AR, Feinberg E, Hickey EJ, Shabanova V, Weitzman C (2021) Parenting stress and its associated components prior to an autism spectrum disorder (ASD) diagnostic evaluation. J Autism Dev Disord 51(10):3432– 3442. https://doi.org/10.1007/s10803-020-04804-w
- Wang H, Hu X, Han ZR (2020) Parental stress, involvement, and family quality of life in mothers and fathers of children with autism spectrum disorder in mainland China: a dyadic analysis. Res Dev Disabil 107:103791. https://doi.org/10.1016/J.RIDD. 2020 103791
- Wiggins LD, Baio J, Catherine Rice E (2006) Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. J Dev Behav Pediatr. https://doi. org/10.1097/00004703-200604002-00005
- Woodgate RL, Ateah C, Secco L (2008) Living in a world of our own: the experience of parents who have a child with autism. Qual Health Res 18(8):1075–1083. https://doi.org/10.1177/1049732308 320112
- World Health Organization (1996) WHOQoL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996 (Issue December). WHO, Geneva
- Zaidman-Zait A, Mirenda P, Duku E, Szatmari P, Georgiades S, Volden J, Zwaigenbaum L, Vaillancourt T, Bryson S, Smith I, Fombonne E, Roberts W, Waddell C, Thompson A (2014) Examination of bidirectional relationships between parent stress and two types of problem behavior in children with autism spectrum disorder. J Autism Dev Disord 44(8):1908–1917. https://doi.org/ 10.1007/s10803-014-2064-3
- Zhou W, Liu D, Xiong X, Xu H, Manchia M (2019) Emotional problems in mothers of autistic children and their correlation with socioeconomic status and the children's core symptoms. Medicine 98(32):1–8. https://doi.org/10.1097/MD.0000000000016794

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

