Parental Reaction to Early Diagnosis of Their Children's Autism Spectrum Disorder: An Exploratory Study

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Abstract This study explores parental reactions subsequent to receiving their child's autism spectrum disorder (ASD)-diagnosis. Seventy seven parents of recently diagnosed children participated in the Reaction to Diagnosis Interview. Within this group, associations between parental reaction to diagnosis, parental and child characteristics and prediagnostic circumstances were analysed. In a sub-sample, the stability of reaction to diagnosis was examined. The majority of parents were classified as 'resolved' regarding their child's diagnosis. Conversely, parents of children with more severe ASD symptoms or non-Dutch parents were more likely to be classified as 'unresolved'. Sub-sample analysis revealed stability of reaction to ASD-diagnosis. The majority of parents adapted well to the circumstances and the care for their child. Autism severity and parental nationality were significant factors affecting parental reactions. Thus, early identification of parental reaction to children's ASD-diagnosis may aid in providing more tailored parental support programs.

Keywords Autism spectrum disorder · Parenting · Resolution · Early diagnosis · Young children

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Introduction

Autism or autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by atypical and delayed development of reciprocal social interaction and communication, and the presence of stereotyped or restricted behaviors and interests [1]. The onset of ASD is before the child's age of 36 months, followed by a chronic course.

Parenting a child with autism is found to be more stressful than parenting typically developing children or children with mental retardation [2–6]. This parental burden is especially associated with children's social deficits [7] and increases even further during times when children need treatment [8]. After diagnosis, parents use several interventions [9]. Although the number of interventions reduces over time, parents experience permanent stress [10]. Particularly, maternal stress may increase over time, associated with more (social) environmental demands when the child becomes older [11, 12]. Parental coping style appears to be an important moderator of stress in parents of children with ASD. While lack of coping leads to negative parental outcome, such as depression, isolation and spousal relation problems, active problem solving was found to reduce stress [13–15]. Parental coping style is associated with parent's personality, which was found to be mediated by parental efficacy [16]. Parental efficacy refers to Bandura's [17] theory of self-efficacy with respect to parenting, meaning parents' perceived confidence in their ability to raise their child successfully. Greater parental efficacy was found to increase parents' adjustment of the challenging demands while raising their child with ASD [18, 19]. Adjustment, including rearranging daily life was found a continuous activity of parents in order to cope and to adapt to their child's deficits associated with ASD [20]. Therefore, parent's experiences of rearing stress, their

feelings of efficacy, the child's severity of symptomatology and its age are expected to be associated with parental coping strategies to their child's ASD.

Regardless various coping strategies, levels of stress and timing to adapt to the child's disabilities, a commonality is that parents' hopes and expectations for their child's development and future functioning are challenged by the diagnosis of ASD. Former expectations need to be changed into new, more realistic ones [21]. Letting go of the old expectations can cause emotional pain and has been compared to a process of grieving. Marvin and Pianta [22] describe the expressed feelings of such grieving as (non)resolution with respect to the diagnosis of an atypically developing child. The concept of 'resolution of diagnosis' is based on attachment theory and research [22–24]. Parents who come to terms with their child's diagnosis manage to control their emotions and deal with the new situation of their child's condition and their own parenthood. Parents with a lack of resolution find it difficult to change their hopes and believes, which results in permanent grieving [22]. Resolution of diagnosis allows integration of the parental experience into an adequate way of caregiving [22, 25]. Adequate caregiving has been associated with parental sensitivity; that is the extent to which parents adequately respond to the needs of the child. Parental sensitivity in turn is associated with securely attached children [25–27]. Both the deviant development of the child, as well as the grief of the parents related to the diagnosis itself can interfere with adequate caregiving.

Parental resolution of the child's diagnosis can be assessed with the 'Reaction to Diagnosis Interview' (RDI) [22]. RDI-outcomes are divided into two main classifications: 'Resolved' or 'Unresolved' [28–30]. A resolved classification indicates successful adaptation and coping, having moved on from the crisis of the diagnosis. On the contrary, parents classified as unresolved show ongoing negative emotions associated with the diagnosis. Resolved and unresolved classifications are labeled in separate categories [30–33]. Parents classified as resolved move on with their lives by so called action, thinking or feeling oriented coping strategies. An action oriented coping strategy is characterized by supporting the child's functioning through direct action, such as arranging resources or adapting routines of caregiving which emphasize the child's special needs. Thinking oriented parents focus on knowing and understanding the child's condition, while feeling oriented parents demonstrate balanced emotions with respect to the experience. In contrast, parents with an unresolved main classification on the RDI show little or no change in response to the child's diagnosis. They seem to be stuck in negative emotions which obstruct adaptation of the diagnosis and demonstrate inadequate coping strategies, e.g. blaming others, false believes of the child's condition, or simply ignoring what is going on.

To our knowledge, only a few studies used the RDI when a child was diagnosed with ASD [25, 31, 34]. Sample sizes of these studies range from 45 to 63 children. All three studies used a cross sectional design. Associations were found between resolution of diagnosis and optimal maternal interaction style [34] or between resolution of diagnosis and children's security of attachment [25]. Similar findings were described in previous studies of children who were diagnosed with other developmental disabilities. However, no associations were found between parents' classifications as resolved and child characteristics (age, gender, autism severity, mental age, daily living skills), parental characteristics (age, gender, IQ, traits of broad autism phenotype, maternal depressive symptoms, social economic status), or the time interval between the child's diagnosis and the RDI-assessment [31, 34]. Nevertheless, the mean duration of time since parents received their child's diagnosis and RDI-assessment was rather long, ranging from nearly 10 months to more than 4 years. Moreover, these studies lack information on stability of RDI-results over time. Two previous longitudinal studies looking at children with (1) neurological or disfigurement congenital disorders and (2) cerebral palsy only, demonstrated predominant stable outcomes at the main classifications of parental reaction to children's diagnoses [28, 33] and changes with respect to RDI-subclassifications [33]. In these diagnostic populations, associations were found between RDI-outcomes and the type or severity of diagnosis. Unresolved classifications of the RDI were found overrepresented in parents of children with a neurological diagnosis and lower mental ability [28] and in parents of children with more severe forms of cerebral palsy [35].

In families of children with autism, the period between noticing deviant development in the child and receiving the ASD-diagnosis may be critical to parental grief and parents' coping strategies. Parents who report first suspicions of their child's developmental problems are more likely to receive early diagnosis than parents without concerns [36, 37] and therefore may be more able to cope with the diagnosis. Parents benefit from early diagnosis, especially when the delay between parents' first suspicions and time of receiving a final ASD-diagnosis is minimal [38]. However, a significant diagnostic delay of more than 2 years is found [39, 40]. It is not clear how this diagnostic delay contributes to parents' reactions to the diagnosis. After screening, the parental compliance to professional advice varies greatly from early compliance (when the child is about 2 years old) to late and non-compliance (when the child is younger than 18 months) [40]. These findings suggest that some parents need time to accept the possibility of developmental problems.

The aims of the present study were to explore associations between RDI-classifications and parent and child

characteristics as well as prediagnostic circumstances, as soon as possible after receiving the child's ASD-diagnosis. We hypothesized that severe autism symptomatology may obstruct parents in their resolution to the child's diagnosis, especially at the critical moment of receiving it. In addition, we expected that parents who identified their child's autism characteristics in early childhood themselves may be more likely to cope in an adequate, supportive way, than parents who did not recognize their child's special needs until receiving the ASD-diagnosis. Secondary, in a sub-sample of parents who continued to use regular care after the diagnostic phase, we explored stability of parental reaction to diagnosis over time.

Method

Procedure

Parents were invited to participate directly after receiving their child's diagnosis of ASD, and as part of a larger, randomized controlled intervention study. Parental reaction to diagnosis was assessed at baseline before randomization. Parents were asked to complete questionnaires to collect data on parent and child characteristics. Demographic data were collected during the diagnostic phase (e.g. parental age, marital status, postal area, education and occupation). After 7 months, a follow up assessment of reactions to their children's diagnosis was acquired from parents who participated under control conditions, receiving usual care. We excluded longitudinal data of parents who received the experimental intervention, because of potential intervention effects. The experimental intervention was a standardized attachment-based program, which might influence parents' reaction to the child's diagnosis, because of improved parent–child interactions. Participants were included from June 2008 to April 2012. Both parents of the child signed written informed consent before participation. The Medical Ethics Review Board of the University Medical Center Utrecht in the Netherlands (UMC Utrecht) approved the study protocol.

Care as Usual

After parents received an ASD-diagnosis of their child at the Department of Psychiatry of the UMC Utrecht, nursing care is usually offered. Nursing care consists of home training, regarding parents' questions about practical issues, and simultaneously parental guidance at the hospital. The number of home-visits and sessions at the hospital averaged about five visits, but they vary based on parent's preferences. In addition, group meetings with parents were provided for psychoeducation about ASD in general. The

psychiatrist may prescribe medication to treat comorbid problems by indication. Parents can also receive support from external care providers.

Participants

Seventy-seven primary caregivers (90 % mothers) of a child diagnosed with ASD (86 % boys) at the UMC Utrecht were interviewed. Their employment ranged from 0 to 50 weekly hours ($M = 19.36$; $SD = 13.97$). The majority of families (96 %) were assigned a moderate to high level of SES. Of the parents 82 % were married, 8 % were divorced and 10 % were a single mother. Children's age ranged from 16 to 61 months ($M = 42.87$; $SD = 9.99$). More than half of the children were first born (60 %). Children's developmental level ranged from mental retardation to high functioning. In 53 % of this sample, the interval between child's chronological age and age equivalent of language development were found more than 6 months. Twelve percent of the children were raised bilingually. Children were diagnosed as having ASD by a board certified child psychiatrist according to extensive developmental history, all medical files, a semi structured observation (Autism Diagnostic Observation Schedule-Generic) and classification of the Diagnostic and Statistical Manual of Mental Disorders 4th Edition-Text Revision (DSM-IV-TR) [1]. The DSM-IV-TR includes Pervasive Developmental Disorders; Autistic Disorder (AD) and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS), and other ASDs; Asperger's Disorder, Rett's Disorder and Childhood Disintegrative Disorder. Of the children, 67 % were diagnosed with AD, and 33 % were diagnosed with PDD-NOS (see Tables 1, 2). At the first assessment, the duration of time since receiving the diagnosis was 5 weeks on average ($M = 5.19$; $SD = 4.14$). The majority of children received ASD (with or without comorbid mental retardation) as the first and only diagnosis. Next to the ASD-diagnosis, some children (36 %) received a diagnosis or a combination of diagnoses (11 % of the 36 %) regarding somatic conditions; chronic obstructive pulmonary disease (21 %), sensory deficits (12 % auditory and 6 % visually problems), epilepsy (6 %), growth disorder (4 %), congenital heart muscles disease (3 %), metabolic disease (1 %).

Instruments

Autism Diagnostic Observation Schedule-Generic (ADOS-G)

The ADOS-G [41], offers the opportunity to quantify deficits across the autism spectrum, controlling for effects of language and cognitive delay, in individuals with significant impairments. ADOS-G total score is the cumulative score of five test domains: communication, social

Table 1 Child and parent characteristics

Variable (N = 77)	Range	Mean	SD
Child characteristics			
Child's autistic characteristics (ADOS-G, total sum score)	8–47	26.12	9.80
Child's developmental level (MSEL, early learning composite standard score)	49–124	73.69	22.03
Child's language comprehension age equivalent (months)	7–75	32.45	16.91
Child's language production age equivalent (months)	7–75	32.08	16.07
Parent characteristics			
Mother's age (years)	25–52	36.03	4.83
Father's age (years)	25–56	38.39	6.19
Primary caregiver's age (years)	25–52	36.55	5.04
Child and parent questionnaires outcomes			
Child's challenging behaviors (ABC score)	7–136	52.64	25.13
Mother's autistic traits (AQ score)	2–39	13.31	7.48
Father's autistic traits (AQ score)	4–35	14.63	6.20
Primary caregiver's autistic traits (AQ score)	2–39	13.62	7.13
Parental personal efficacy (PEQ score)	−6 to 44	22.58	10.61
Parental stress (PDH score)	3–53	23.18	13.10

ABC Aberrant Behavior Checklist, *ADOS-G* Autism Diagnostic Observation Schedule–Generic, *AQ* Autism Quotient, *MSEL* Mullen Scales of Early earning, *PDH* Parental Daily Hassles, *PEQ* Parental Efficacy Questionnaire

Table 2 Sociodemographics

	Mother % (n)	Father % (n)	Primary caregiver % (n)
Dutch nationality	87 % (67)	91 % (70)	90 % (69)
Low level of education (<2nd degree)	14 % (11)	23 % (18)	14 % (11)
Moderate level of education (2nd degree)	44 % (34)	40 % (31)	48 % (37)
High level of education (bachelor/master degree)	42 % (32)	33 % (25)	38 % (29)
Education unknown		4 % (3)	

Not Dutch nationality: Chinese, Colombian, Israeli, Irish, French, Moroccan, Nigerian, Russian, Somalia, Turkish

reciprocity, play, stereotypic behavior and other problems. A high ADOS-G total score refers to severe autistic symptoms. The ADOS-G consists of four modules. In the current study, children were assessed using module 1 (*n* = 42) and module 2 (*n* = 35), based on their individual level of expressive language. The child psychiatrist, who was certified for ADOS-reliability, administered the ADOS-G, during the diagnostic phase, prior to this study.

Mullen Scales of Early Learning (MSEL)

The MSEL [42] is a standardized developmental test that yields a mental age score for children between three and 68 months of age. The MSEL consists of five test domains, one measuring cross motor skills (not administered in the current study), and four cognitive domains: (1) visual reception, (2) fine motor skills, (3) receptive language and (4) expressive language. The final early learning composite standard score is a combination of non-verbal (domain 1 and 2) and verbal composites (domain 3 and 4), which ranges from low to high cognitive functioning. The test was administered by a trained clinical psychologist at baseline assessment.

Language Development

The Reynell test for Dutch language comprehension [43] and the Schlichting test for Dutch language production [44] were used in individual tests, administered by a trained psychologist or speech language therapist at baseline and follow-up assessment. The Reynell and Schlichting tests evaluate receptive and expressive language respectively, for children between 14 and 75 months of age. If children were not able to cooperate in the individual tests (37 % of this sample), parental reports were collected by Dutch versions of the MacArthur-Bates Communicative Developmental Inventories (CDIs) [45–48]. CDIs consist of three forms, corresponding with different age groups; (1) 'Word and Gestures' (8–16 months of age), (2) 'Words and Sentences' (16–30 months of age) and (3) 'CDI-level III' (30–37 months of age), assessing vocabulary comprehension and production. The inventories were also used for children with impaired language development beyond the specified age ranges [49]. Its validity was shown in children with and without language delay [50] and confirmed in parental reports of early language development in children with autism, using CDIs [51, 52]. In the current study, the level of children's language

development was based on the converted age equivalents of total language comprehension scores of the Reynell or N-CDI, and total word-production scores of the Schlichting or N-CDI.

Aberrant Behavior Checklist (ABC)

The ABC [53] is a 58-item questionnaire to assess children's challenging behavior. On a 4-point rating scale, outcome ranges from no to severe challenging behaviors (scores 0–174). It comprises the following five factors: (1) irritability, agitation, crying; (2) lethargy, social withdrawal; (3) stereotypic behavior; (4) hyperactivity, noncompliance; (5) inappropriate speech. In an ASD sample, factor analysis indices a moderate fit for the five factor solution [54].The ABC was found promising for assessing the severity of autism behaviors in early childhood [55]. Parents completed the questionnaire at baseline and follow-up. Internal consistency of the scale (Cronbach's alpha) was .94 ($n = 75$). Missing values were randomly scattered across items and subjects and no variable missed more than 10 % of values. Mean scores within the observed group were imputed before the total set was entered for analyses.

Socio-Economic Status (SES)

SES was based on status scores 2010 of postal areas ($M = .17$; $SD = 1.16$). Status scores are derived from level of education, employment and income [56]. A higher status score refers to higher SES. In this sample, SES ranges from −1.84 to 2.23 ($M = .94$; $SD = .84$).

Parental Efficacy Questionnaire (PEQ)

The PEQ is a 22-item, self-report questionnaire on a 5-point rating scale, which ranges from low to high efficacy (scores −44 to 44). The PEQ is based on Bandura's [57] general theory of personal efficacy and has been adapted for parents of young children [58]. The instrument assesses parents' feelings of competence in child rearing, particularly when parents meet stressful circumstances [11]. The PEQ was administered at baseline and follow-up. Cronbach's alpha for internal consistency was .86.

Parental Daily Hassles (PDH)

The PDH is a 20-item instrument developed by Crnic and Greenberg [59] to assess the strains and stresses accompanying child rearing. It contains descriptions of typical everyday life events in parent–child interactions, which are rated by the parent on a 5-point rating scale for frequency of occurrence of the hassle (scores 0–80). The PDH was administered at baseline and follow-up. Cronbach's alpha for internal consistency was .90.

Symptom Checklist (SCL-90)

The SCL-90 [60] is a 90 item, self-report questionnaire, rated on a 5-point scale to indicate mental health status of the parents. The instrument is designed to measure agoraphobia, anxiety, depression, somatic complaints, insufficiency in thinking and acting, distrust and interpersonal sensitivity, hostility, sleeping problems and a rest-category. The total score for psychoneuroticism is based on the sum of the sub- and rest-categories. Psychoneuroticism indicates a general level of psychoneurotic-somatic complaints. In this study, the norm table of the typical population was used; ranging from very low (score 90) to very high level of complaints (score ≥183) [M typical population = 118.28, $SD = 32.38$ (60: pg. 107)]. Internal consistency of the total scale (Cronbach's alpha) was .97. Missing items on the total scale were less than 5 % (a maximum of two items per subscale and no items on the subscale sleeping problems). In these cases, the (estimated) scores on each subscale were computed based on the real scores (60: pg. 97).

Autism Quotient (AQ)

The AQ [61] is a brief, self-administered questionnaire to screen and quantify autistic traits in adults with normal intelligence, including the following domains; (1) social skill; (2) communication; (3) imagination; (4) attention to detail and (5) attention and switching. It comprises 50 items, regarding personal preferences and habits, which are rated on a 4-point Likert scale. A high AQ score (>32) suggests clinical levels of traits associated with the autistic spectrum. An above average score (23–31) shows some autistic traits. An average score (11–22) is based on the scores of most women (score 15) and most men (score 17) in a typical population. The Dutch translation of the AQ was found to have satisfactory internal consistency (Cronbach's alpha of the total AQ score was .71–.81) and test–retest reliability was .78 for the total AQ score [61]. Cronbach's alpha for internal consistency in our sample was .88. There were no missing values (<.03 %).

Reaction to Diagnosis Interview (RDI)

The RDI [22] is a semi-structured narrative interview intended for research use on populations of parents with chronically ill or handicapped children. This interview is designed to measure parents' reactions to and coping strategies for dealing with the diagnosis of their child with a disabling condition or illness. The interview consists of a series of questions eliciting the parent's beliefs, memories and emotional reactions to the news of their child having an illness or disability (see Table 3). The interview takes approximately 10–15 min. The outcome is classified in Resolved with three

Table 3 Reaction to Diagnosis Interview based on Marvin and Pianta [22] and specified to diagnosis of autism spectrum disorders

1. Looking back, when did you first realize that (child's name) had a medical problem?

2. What were your feelings at the time of this realization?

3. Later you visited the child psychiatrist. Tell me exactly what happened when you learned of (child's name) ASD-diagnosis? Where were you, who else was there, what were your thoughts and feelings at that moment?

4. Have these thoughts and feelings changed since receiving this diagnosis?

5. Did you, to your opinion, get a clear picture of (child's name) ASD characteristics, at the moment when you received the diagnosis?

6. Can you describe (child's name) ASD characteristics at this moment? And what are your expectations of (child's name) future?

7. Parents sometimes wonder or have ideas about why they have a child with ASD. Do you have anything like that that you wonder about? (prompt if necessary: for example, some parents feel that they might have done something to contribute to their child's condition, others have a religious contemplation or considering raising a child with ASD as a special task in life. What do you wonder about?)

8. Have these considerations changed over time?

ASD autism spectrum disorder

subclassifications: action, thinking or feeling oriented or Unresolved with six subclassifications: emotionally overwhelmed, angrily preoccupied, neutralizing, depressed/passive, cognitive distortions or disorganized/confused.

According to the RDI manual, the interviews were videotaped, transcribed and coded [22; Dutch version J. Stolk, unpublished manual]. Clinimetric studies revealed adequate intercoder reliability of RDI classifications [28, 30]. In this study, the first authors (IP and FN) were trained in the coding system by a certified trainer. Intercoder agreement was 100 % on the main classifications and 80–90 % on the subclassifications. Based on 18 % of random selected interviews of the current study, the inter-rater reliability on the main classifications was kappa = .87, $p < .01$ and on the subclassifications was kappa = .75, $p < .01$. Additionally, all disagreements were conferenced to unanimity of opinion, prior to entering into the dataset.

Results

Since we included the primary caregiver of the child, our sample comprised a minority of 10 % fathers ($n = 8$). Independent sample t tests (two-sided) and Chi squared tests were performed to detect differences between male and female primary caregivers. Distributions of employment (weekly hours) revealed a difference [χ^2 (18, n = 77) = 44.29, $p < .01$] between fathers ($M = 37.04$, $SD = 11.29$) and mothers ($M = 18.34$, $SD = 13.22$). No gender differences were found in other parental characteristics and parental reports (all $p > .05$). In this sample, 8 % of the primary caregivers as well as 8 % of all parents reported an above average level or high level of autistic traits. Parental mental health showed an above average level of complaints, including a high level of depression and above average levels of somatic complaints and insufficiency in thinking and acting compared to typical population levels (see Table 4).

Table 4 Parental mental health by SCL-90

(Sub)category (N = 77)	Mean	SD	Norm
Agoraphobia	7.57	1.14	Low to average
Anxiety	13.84	4.29	Average
Depression	25.47	8.79	High
Somatic complaints	18.96	6.64	Above average
Insufficiency in thinking and acting	15.26	6.36	Above average
Distrust and interpersonal sensitivity	24.08	7.08	Average
Hostility	7.93	2.32	Average
Sleeping problems	4.75	2.17	Average
Psychoneuroticism	129.34	35.58	Above average

SCL-90: Symptom Checklist, norm based on typical population

Reaction to Diagnosis and Cross-Sectional Associations

The first assessment classified 75 % ($n = 58$) of the parents as resolved. Proportion tests computed with Medical Calculation revealed 95 % confidence interval of 64 % to 84 %. The proportion of parents classified as resolved was significantly higher than in previous studies: 40 % of the parents in ASD-studies, $p < .01$ and 60 % of the parents in all studies, $p < .01$ (see Table 5).

Parents with a resolved RDI-classification were characterized mostly with an action oriented strategy (62 %, $n = 36$), followed by thinking oriented (26 %, $n = 15$) and feeling oriented strategies (12 %, $n = 7$). Parents classified as unresolved ($n = 19$) were subclassified as neutralizing (32 %, $n = 6$), emotionally overwhelmed or depressed/passive (both 26 %, $n = 5$) and angrily preoccupied (16 %, $n = 3$).

Independent sample t tests (two-sided) and Chi squared tests demonstrated associations between children's autism severity and parental origin. Unresolved RDI-classifications were overrepresented in parents of children with higher levels of autistic symptoms, based on the ADOS-G

Table 5 RDI-main classifications of various studies at first assessments

References	Child's diagnosis	Sample	N	Resolved n	Unresolved n	Resolved %
Milshtein et al. [31]	ASD	Mothers	61	22	39	36
Milshtein et al. [31]	ASD	Fathers	60	30	30	50
Oppenheim et al. [25]	ASD	Mothers	45	15	30	33
Total ASD studies				67	99	40*
Marvin and Pianta [22]	CP	Primary caregivers	70	33	37	47
Marvin and Pianta [22]	CP	Primary caregivers	68	31	37	46
Rentinck et al. [33]	CP	Parents	38	31	7	82
Schuengel et al. [35]	CP	Parents	255	208	47	82
Lord et al. [65]	PKU	Mothers	52	36	16	69
Lord et al. [65]	PKU	Fathers	47	36	11	77
Marvin and Pianta [22]	Epilepsy	Primary caregivers	23	13	10	57
Sheeran et al. [32]	CP or epilepsy	Mothers	97	47	50	48
Barnett et al. [28]	Congenital disorder	Mothers	44	20	24	45
Kearney et al. [29]	Psychiatric disorder	Mothers	33	18	15	55
Total studies				540	353	60*

RDI Reaction to Diagnosis Interview, *ASD* autism spectrum disorder, *CP* cerebral palsy, *PKU* phenylketonuria

* $p < .01$ compared with 75 % resolved classifications of primary caregivers in this study (proportion test with Medical Calculation)

total score (F (72, -2.00) = .13, p = .050). Also parents of other than Dutch nationality were classified more often unresolved than Dutch parents [χ^2 (1, n = 77) = 6.87, p = .02]. Hierarchical regression was employed to determine whether child autism severity or nationality of the primary caregiver predicted parental resolution status. In the first step child autism severity contributed significantly to the prediction (5 %) of parental resolution status F (1, 73) = 3.99, p = .050. At step two adding nationality of the primary caregiver to the equation, 13 % of the variance was explained, F (2, 73) = 5.28, $p < .01$. No other associations were found between RDI-outcomes and parents' characteristics (age, level of education, marital status, SES, traits of broad autism phenotype and mental health), parental efficacy, parental daily hassles, and child characteristics (age, gender, birth order, challenging behaviors, developmental level, language age equivalents, and bilingualism). Furthermore, prediagnostic circumstances, including parental recognition (83 % of the parents detected their child's problems by themselves), children's age of primary ASD-suspicions (M = 16.99 months, SD = 9.20) and the time since diagnosis revealed no associations with resolution/nonresolution of diagnosis either.

Stability of RDI-Classification

After 7 months, we analyzed data of parents who received care as usual and completed both RDIs (N = 35). A total of 83 % of parents versus 77 % at baseline, demonstrated resolved RDI-outcome over time. Repeated measures

revealed that the majority of parents (83 %, n = 29) continued the same RDI-classifications since the first assessment (RDI at time 1: M = 1.23, SD = .43; RDI at time 2: M = 1.17, SD = .38, $p > .05$) (see Fig. 1). Four parents (11 %) switched from unresolved to resolved classifications (all action oriented). Two parents (6 %) switched from a resolved classification into an unresolved, depressive/passive category.

Half of the parents (n = 18) at stable main category level, whether resolved or unresolved, changed subclassifications. Within the group of parents with resolved RDI-outcomes (n = 25) classifications of action oriented strategies lessened in favor of feeling oriented classifications (see Fig. 2).

At the subcategory level of unresolved reports, all three parents with angrily preoccupied subclassifications changed into a different subclassification, i.e. one into 'emotionally overwhelmed', one into 'neutralizing' and one into 'cognitive distortions'. Although these subclassification-fluctuations within the classification of stable resolved/unresolved reaction to diagnosis are of interest, the number of changes in this sample is too small for further exploration.

To explore potential associations of parental coping strategies as measured by (un)changed RDI-subclassifications with severity of the child's ASD and age as well as the differences between assessments over time in parental daily hassles and reported feelings of efficacy, we divided the group in four categories: (1) remaining resolved, (2) remaining unresolved, (3) changing from unresolved into
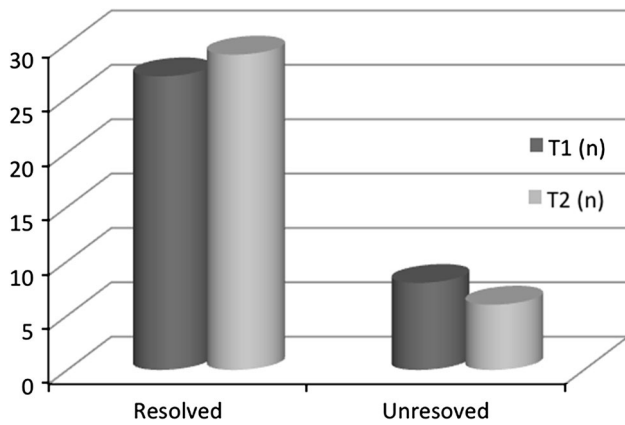
Fig. 1 Number of parents classified as resolved or unresolved at 5 weeks (*T1*) and 30 weeks (*T2*) after diagnosis
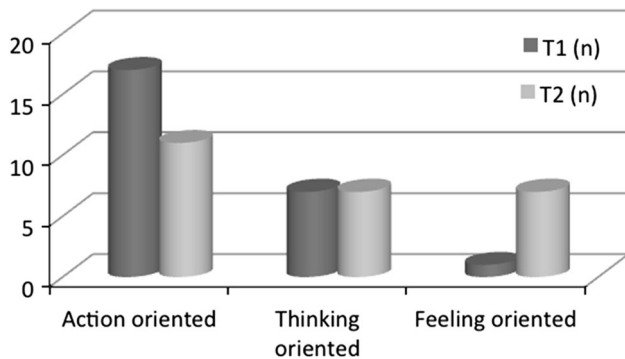
Fig. 2 Number of parents in subclassifications of continued resolved classifications (n = 25), at 5 weeks (*T1*) and 30 weeks (*T2*) after diagnosis

resolved, and (4) changing from resolved into unresolved. Using one-way analysis of variance, we found that the group of parents who changed from unresolved into resolved resolution showed the highest increase in parental efficacy $F(3,31) = 3.92$, $p = .02$ (see Table 6).

Discussion

In the present study, we explored associations of parents' and children's characteristics and prediagnostic circumstances with parents' reactions to diagnosis. We found that the majority of parents came to terms with their young child's ASD soon after receiving the diagnosis. Nevertheless parents of children with more severe autistic symptoms and parents with nationalities other than Dutch were more often classified as unresolved. No other associations between resolution/nonresolution and parental or child characteristics were found. Furthermore, administration of the RDI directly after receiving the diagnosis, as well as prediagnostic circumstances revealed no associations with parental resolution to diagnosis.

Additionally, we focused on short-term stability of reaction to diagnosis of parents who received usual care after the diagnostic phase. About 7 months after receiving the diagnosis, most of the parents demonstrated stable RDI-classifications. Changes of resolved RDI-outcome were found in advance of changes into unresolved classifications. Stability of parents' reaction to diagnosis seems to be influenced by the level of parental efficacy. Overall, the main RDI-classifications remained stable while subclassifications changed over time, comparable with previous longitudinal findings of Barnett et al. [28] and Rentinck et al. [33].

In this study, we found a majority of parents classified as resolved. This is in line with Kandel and Merrick [63], who report that parents of children with developmental disabilities experience positive emotions towards child rearing, despite frequent confrontations with higher levels of distress. Our finding is also consistent with broader research examining coping mechanisms in parents of children with ASD. Parents are generally capable to adapt the challenges of raising a child with ASD, using for example, social support [11, 64]. Mobilizing family members and community members is one of the effective coping strategies parents use to manage daily stressors [21,

Table 6 One way ANOVA of effects of (un)changed RDI-classifications on child autism severity, child age and differences over time of parental daily hassles and reported feelings of efficacy (N = 35)

T1: T2:	Group								F	p
	Resolved Resolved		Unresolved Unresolved		Unresolved Resolved		Resolved Unresolved			
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
ADOS-G total score	25.80	9.72	29.75	09.61	31.75	10.24	25.50	20.51	.51	.68
Age child in months	43.30	9.92	40.12	18.23	44.41	09.14	41.49	20.22	.12	.95
PEQ de- or increase at T2	01.57	6.77	07.62	10.00	15.00	07.94	−2.00	04.24	3.92	.02
PDH de- or increase at T2	01.71	9.19	−1.42	07.53	−9.00	11.36	.79	08.19	1.27	.30

ADOS-G Autism Diagnostic Observation Schedule–Generic, *ANOVA* analysis of variance, *PDH* Parental Daily Hassles, *PEQ* Parental Efficacy Questionnaire, *RDI* Reaction to Diagnosis Interview, *T1* baseline assessment, *T2* 7-months follow-up assessment

64]. However, some parents may need more time to benefit from (in)formal support. Independently of SES, we found that parents of newly diagnosed children with other than Dutch nationality showed more often unresolved RDI-classifications. This finding cannot be explained by a specific cultural background, since this group of parents consisted of a diversity of nationalities (Chinese, Colombian, Israeli, Irish, French, Moroccan, Nigerian, Russian, Somalia and Turkish). Generally, accessibility to resources varies among countries, because of cultural and language differences, influencing parental stress experiences, related to RDI-outcomes [35, 65]. Otherwise, the level of family support may be an influencing factor, because parents originating from foreign countries may be limited in seeking informal support due to mental and physical distance to their relatives. However, the amount of non-Dutch parents in this sample is too small for scientific interpretation.

Surprisingly, the brief time-interval since parents received the diagnosis of the child and the RDI, did not result in a high proportion of unresolved RDI-scores. On the contrary, the percentage of parents classified as resolved in this study was significantly higher compared to other studies regarding ASD [25, 31], but consistent with studies of other diagnoses of Lord et al. [65], Rentinck et al. [33] and Schuengel et al. [35] (see Table 5). Inconsistencies in findings between this study and other studies regarding ASD can be explained by heterogeneous samples (both parents, only mothers or primary caregivers). Also, proportions of children with AD versus PDD-NOS differ between these studies. AD is considered a more severe form of ASD than PDD-NOS. Previous studies included about 80 % parents of children with AD [25, 31] in contrast with 67 % parents of children with AD in our sample. Fewer children with AD may probably decrease the number of parents with nonresolution states to diagnosis. This is in line with our finding of significantly more parents who expressed unresolved feelings and thoughts of their child's newly diagnosis when ASD-symptoms were more severe. Nevertheless, regarding the association between autism severity and parental resolution, in this study the nationality of the primary caregiver seems to be a stronger predictor for the risk of coping problems with the child's ASD-diagnosis. Besides acknowledgement of autism severity or parent's nationality, to be able to detect parents at risk for unresolved reactions to their child's diagnosis, the RDI may be an important and useful instrument in clinical practice. Knowledge of parental reaction to diagnosis may advance parental support, including early intervention programs to promote adequate caregiving.

Similar to prior research [29, 31, 34], this study revealed no other associations between parental reactions to diagnosis and (demographic) parental and child characteristics.

Although parents reported above average levels of psychoneuroticism, including high levels of depression, no significant correlation was found between parent's mental health condition and reaction to ASD-diagnosis. This result confirmed findings of Wachtel and Carter [34], despite their modified RDI-coding system into a continuous variable with multiple dimensions versus a dichotomous variable in this study. Contrary, another study [29] showed child rearing stress in combination with maternal depression to be predictive of unresolved RDI-classifications. This however, was found in a heterogeneous sample of school-age children with various psychiatric disorders.

Analogous to the study of Milshtein et al. [31], no association was found between reaction to ASD-diagnosis and parental autistic traits. Mild behavioral characteristics that resemble the deficits as seen in ASD, are often found in non-affective first-degree relatives of individuals with ASD, the so called 'broad autism phenotype' [66–69]. In particular, parents of children with ASD scored higher on AQ-scores, compared to parents of typically developing children [70–73]. In this study, the majority of parents revealed an average AQ-score. An explanation may be that the time of measuring influences this finding. During administering the RDI, parents often explained that they did not acquire a full understanding of their child's symptomatology when they received the diagnosis, despite long lasting suspicions and challenging behaviors of the child. The process of recognizing the child's autistic characteristics completely and then to extrapolate these characteristics to one's own, may need some time. In contrast, parents may underreport autistic traits, because they can interpret the AQ-items clinically [74, 75]. One way or the other, parents might have slightly misjudged their own characteristics related to ASD as a usual risk of self-reporting. Also, psychometric properties of the AQ were recently discussed. Although the Cronbach's alpha of .72 for internal consistency of the AQ was found satisfactory, the values of two other instruments to assess broad autism phenotype were found somewhat higher (Cronbach's alpha of .90 and .95) [76]. However, the use of the AQ in our study was consistent with the previous study regarding associations between parents' broad autism phenotype and RDI-outcome [31]. Furthermore, low AQ-scores in the current sample could be explained by the majority of mothers. Previously, mothers of children with ASD were found to report lower total AQ-scores than fathers [62, 72, 74, 75] and even lower or similar total AQ-scores than mothers of typical developing children [74, 75].

In a subsample of parents who received general care at the university hospital, a longitudinal pilot of parental reaction to children's ASD-diagnosis was accomplished. In line with studies of populations with other neurological disorders [28, 33], the majority of parents showed stability

of their reactions to diagnosis. Changes of the main classification shifted to higher percentages in resolved categories than to the opposite. Furthermore, our study replicates past findings regarding changes in subclassifications with respect to children's diagnosis [33]. The predominant prevalence of action oriented strategies may be explained by a diagnostic delay of 2 years on average. When parents finally receive the child's diagnosis, they may be eager to act, resulting in an action oriented classification. Additionally, several months later, when (practical) support is more balanced, parents have the opportunity to cope according to different strategies. Coping strategies may synchronize with parents' characters, which results in higher levels of thinking and feeling orientations. Other parental characteristics, such as parental efficacy are also important to consider. We found a substantial increase of parental efficacy associated with a shift from unresolved into resolved RDI-classification, while a decrease in parental efficacy over time showed an opposite change of resolved into unresolved classification. Variances of RDI-main and -subclassifications over time are of interest to detect phases within the adaptation process of parental coping with children's ASD, though the frequency of classification-changes in this study is too low for analysis. In order to understand the mechanism behind this process a qualitative study design regarding parental experience with respect to diagnosis over time may be appropriate. Qualitative research allows for in-depth interviewing [77], which may identify important themes of parents' hopes and believes for their child's development. Also, several follow-up assessments may reveal more insight in the course of parents' reaction to diagnosis over time and to what extent parental characteristics (e.g. parental efficacy) and other factors, such as social support, may be of influence.

We studied RDI-classifications of parents in a moderate sample of 77 young children with ASD. The mean time-interval of 5 weeks since parents received their child's diagnosis and RDI-administration contrasted with the larger time-intervals of previous studies in ASD-samples. This early time-point of assessment contributes to existing findings with respect to the dynamic process of adaptation. However, several limitations of this study should be addressed. Response and selection bias may underlie the lack of association between several parental characteristics and the reaction of parents to ASD-diagnosis. Firstly, self-report questionnaires were used, which can evoke politically correct answers. Secondly, parents were invited to the RDI as part of an intervention study, which recruited generally motivated and active parents, resulting in an overrepresentation of parents with an 'action oriented' subclassification. Action oriented coping emphasizes orientation to activities and caregiving towards the child's

special needs, such as the use of interventions. Finally, the majority of included parents had a moderate to high SES. Future longitudinal research is needed in a larger sample with more heterogeneous SES and demographics to examine parental reaction to their child's ASD-diagnosis and its associations with aspects of adjustment, such as the level of (informal) support and phases within the process of adaptation.

Summary

Parents of children with ASD showed high levels of acceptance and active adaptation to the recent diagnosis of their child. This parental coping does not depend on experienced levels of parental stress or the presence of depressive moods. Parental reaction to diagnosis of their child is associated with the severity of children's autistic symptomatology and parent's nationality. To identify families at risk for unresolved reactions to their child's diagnosis can be of clinical relevance. Knowledge of parent's resolution/nonresolution to diagnosis can contribute to tailored parental support and intervention programming. Whether parents show resolved or unresolved RDI-classifications, the subtype categories appear to be dynamic. Future (qualitative) research is needed on parental experiences with respect to their child's ASD-diagnosis over time.

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