



Published in final edited form as:

Autism. 2009 July ; 13(4): 375–387. doi:10.1177/1362361309105658.

Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay

It is well established that mothers of children with developmental and psychiatric difficulties are at risk for experiencing greater distress than mothers of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002; Dumas, Wolf, Fisman, & Culligan, 1991; Hauser-Cram et al., 2001; Hodapp, Ricci, Ly, & Fidler, 2003; Johnston et al., 2003; Rodrigue, Morgan, & Geffken, 1990). Several studies suggest mothers of children with autism spectrum disorders (ASD) may experience higher levels of distress than mothers of children with other disabilities (e.g., Gallagher & Bristol, 1989). For example, mothers of children with ASD have demonstrated lower psychological well-being and coping compared with mothers of children with Down Syndrome, Fragile X and cerebral palsy (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Kasari & Sigman, 1997). Mothers of children with ASD also report higher stress and depressive symptoms compared with mothers of children with broadly defined developmental delay (Dumas et al., 1991). Two studies found comparable stress levels in mothers of children with ASD and externalizing disorders (Donnenberg & Baker, 1993; Dumas et al., 1991), but no study to date has found a group of mothers with higher distress levels than mothers of children with ASD. This work has contributed to our understanding of family processes and has provided evidence suggesting mothers of children with developmental disabilities, particularly autism, maybe at risk for a range of challenges to their psychological functioning.

Mothers face unique challenges related to characteristics of children with ASD. Specifically, autism, unlike other forms of developmental disability, impairs social relatedness, which may be emotionally painful for mothers. Many, but not all, children with ASD also exhibit very unusual language and communication patterns, such as stereotyped speech, and odd and ritualistic behaviors. Such behaviors may pose difficulties for mothers when they spend time with their children in public situations, especially when uninformed people may misunderstand or misinterpret the child's behaviors. Thus, characteristics of children diagnosed with ASD may account for increased maternal stress. Alternatively, higher levels of distress in mothers of children with ASD might not be primarily related to the unique challenges associated with ASD. It may be characteristics common to children with a range of developmental disabilities, such as the presence of problem behaviors and impaired adaptive functioning, are present to a higher degree in children with ASD. It may be increased levels of these common child characteristics, and not autism specific characteristics, lead to increased stress in mothers of children with ASD.

There is mixed evidence regarding the contribution of child problem behaviors and impaired adaptive functioning to increased maternal distress. In terms of problem behaviors, research by Konstantareas and Homatidis (1989) found that self-injury was the strongest predictor of parental stress in a sample of 44 children with autism. This finding is consistent with studies of children with non-autistic developmental disabilities in which problem behaviors have emerged as the most consistent child-related source of parental distress (e.g., Baker et al., 2002; Beck et al., 2004; Hauser-Cram et al., 2001; Hodapp et al., 2003). Recent studies have also suggested that this pattern may be present in mothers of children with ASD (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Dumas et al., 1991; Hastings & Brown, 2002). Another potential child characteristic that may contribute to increased parent stress is impaired adaptive functioning. Parents of children with lower daily living skills (a specific facet of adaptive

behavior), may face increased child-rearing responsibilities. For example, children with lower daily living skills need greater assistance with a range of basic activities, from dressing, to bathing, to toileting. These increased demands may lead to increased parenting stress or psychological distress. However, evidence is mixed regarding the relationship between adaptive function and parental distress. Two studies have reported that better adaptive functioning in children is associated with increased maternal well being (Fitzgerald, Birkbeck, & Matthews, 2002; Tomanik, Harris, & Hawkins, 2004). Two studies report no association between parental stress and adaptive skills (Beck et al., 2004; Lecavalier, Leone, & Wiltz, 2006). In the current study, we assessed both child daily living skills and child problem behavior, in addition to child diagnosis, as potential contributors to maternal stress.

The discussion thus far has centered on understanding child characteristics as contributors to maternal parenting stress and psychological distress. However, findings may vary depending upon how parenting stress and psychological distress are measured. For example, Rodrigue, Morgan and Geffken (1990) found that parental stress was higher in parents of children with ASD compared with children with idiopathic developmental delay and typical development, but only on certain dimensions of parental stress. Perceived parental competence and marital satisfaction were lower in parents of children with ASD, but self-blame and disruption of finances and activities were equivalent in the ASD and DD groups. No group differences in family cohesion and mother child interaction were found between groups. Beck and colleagues (2004) found that mothers of children with general delays did not have higher levels of depression or anxiety compared with normative samples, but they did have high parenting-related stress. Greenberg and colleagues (2004) found no differences in overall level of optimism, depression, well being or health among mothers of adult children with autism, Down syndrome and schizophrenia. However, mothers of children with Down syndrome reported closer relationships with their children and correlates of parental stress differed by group.

The present study was designed to investigate the relative contribution of child characteristics including diagnosis, problem behavior, and adaptive functioning, to increased maternal parenting stress and psychological distress in mothers of children with autism. We compared mothers of children with autism to mothers of children with developmental delay without autism to control for unmeasured, general factors associated with raising a child with a disability. The two groups were matched on both cognitive ability and age, allowing inferences about child-related factors that may be related to increased parent stress over and above general child developmental level. We also paid careful attention to the diagnostic status of participating children. We directly evaluated all children in the ASD and DD groups and utilized the research criteria recommended by the NICHD Collaborative Programs for Excellence in Autism (CPEA) to determine diagnostic status (see Method section for detailed description). Prior research on maternal stress has not always distinguished between autism and other developmental disabilities (e.g., Beck, Daley, Hastings, & Stevenson, 2004; Bristol, Gallagher, & Holt, 1993). When prior research did distinguish between autism and other disabilities the diagnostic criteria and diagnostic methods used were often not comparable to current diagnostic criteria and methods. This study will allow investigation of the phenomenon of increased maternal stress in autism using current diagnostic criteria and methods and will directly investigate child characteristics that may contribute to this phenomenon. We measured maternal stress in two ways; first, as it relates to parenting (referred to as “parenting stress” in this paper) and second, as psychological distress (a combination of depressive and anxiety symptom scores on the BSI) in mothers.

The study hypotheses are (1) parenting stress and psychological distress will be higher in mothers of children with ASD compared with mothers in the DD group, (2) children in the ASD group will have increased problem behavior and decreased daily living skills compared with the DD group, and (3) child problem behaviors will be more strongly related to maternal

parenting stress and psychological distress than child daily living skills within both the ASD and DD groups.

Method

Participants

Participants were recruited for a longitudinal study on the neurobiology and developmental course of autism at the XXXX and lived in the XXX metropolitan area. Data reported for this study is from the first wave of data collection when children were preschool-aged. Seventy four mothers and their children participated. Children consisted of 51 diagnosed with autism spectrum disorder (ASD) and 23 with developmental delay without autism (DD). The DD group was matched to the ASD group on a measure of non verbal mental age. This variable was computed from averaging age-equivalent scores on the Mullen Scales of Early Learning Visual Reception and Fine Motor scales (Mullen, 1997). The Mullen is a standardized measure used to assess the developmental level of children from birth to 68 months. The DD group was also matched to the ASD group on chronological age.

Procedure

Participants were recruited through local parent advocacy groups, community agencies, clinics, hospital, and public schools. Participating families were paid for each visit to the University and provided with the results of the research diagnostic examination, including standardized test scores, diagnosis when applicable, and recommendations. The results were provided in a written report and discussed in feedback sessions. On-site child care was provided to siblings of participants when requested by parents. Children were assessed at the University of XXX by a licensed clinical psychologist or doctoral students in clinical psychology under supervision of licensed clinical psychologists. Children in the ASD group met diagnostic criteria for an autism spectrum disorder on both the ADI-R (Rutter et al., 2003) and the ADOS-G (Lord et al., 2003) conducted during the first wave of data collection. The ADI-R and ADOS-G are both standardized measures used to diagnose autism spectrum disorders. The ADI-R is a parent interview and the ADOS-G is a semi-structured play observation. DSM-IV diagnoses using all available information were obtained for children in the ASD sample (36 with autistic disorder and 15 with pervasive developmental disorder not otherwise specified). The procedures were based on the National Institute of Child Health and Development (NICHD) CPEA diagnostic criteria established by Catherine Lord and the CPEA diagnostic subcommittee in May 2003 described in greater detail in Schellenberg et al. (2006). Cognitive test scores, information from family history, medical records and clinical observations made during the course of the research assessments were integrated when assigning the DSM-IV diagnosis for the DD group and the ASD group. Children in the DD group did not meet criteria for an autism spectrum disorder on the ADI-R, ADOS-G, or DSM-IV. All children in the DD group had Mullen Early Learning Composite standard scores and Vineland Adaptive Behavior Composite standard scores less than or equal to 80. The only exception was one child with a Mullen composite of 82 and Vineland composite of 70. All children who had a history of serious traumatic brain injury, significant sensory or motor impairment, major physical abnormalities, or neurological disease were excluded. Children in the ASD group were excluded for the presence of a neurological disorder of known genetic etiology (e.g. Fragile X). This sample is described in greater detail in XXXX. For the purposes of this study, children in the DD group were excluded if they had a sibling with ASD. Characteristics of the two groups are described in Table 1.

The children in each group did not differ in terms of child age, race or non verbal mental age. There were significantly more girls in the DD group, as compared to the ASD group. Mothers did not differ in term of age or education level. Families did not differ on socioeconomic status.

The prevalence of stressful life events was measured by the Negative Life Changes scale of the Life Experiences Survey (LES; Sarason, Johnson, & Siegal, 1978). The LES is a 57-item self-report measure that asks respondents to indicate and rate significant events they have experienced during the preceding 12 months from a list of 47 common events. There were no differences between the groups on the occurrence of negative life changes.

Parenting Stress

Questionnaire on Resources and Stress (QRS; Konstantareas, Homatidis, & Plowright, 1992) self-report questionnaire contains 78 items that measure stress and burden of care in families of children with disabilities. Parents rate their agreement or disagreement on a 4-point scale with questions that tap parental feelings about their child (e.g., “I worry about what will happen to N when I can no longer take care of him/her.” “I have difficulty leaving the house because of N.”). Adequate psychometric properties have been reported. This study used the parenting stress summary score as the measure of parenting-related stress.

Psychological Distress

Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) is a widely-used, parent self-report that measures symptoms of psychological distress. The depression and anxiety subscales, which were highly correlated ($r=.67$), were averaged to create an overall measure of psychological distress. A few mothers decided not to complete questionnaires on their own psychological functioning (ASD $n=3$; DD $n=2$).

Problem Behaviors

Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) is a 58-item measure of problem behaviors known to occur in person with moderate to profound developmental disability with higher scores indicating increased severity of problem behavior. The ABC is a questionnaire that asks the caregiver to rate the child’s behavior over the previous 4 weeks on a 4-point scale (0= not at all a problem, 1=the behavior is a problem, but slight in degree, 2=the problem is moderately serious, 3=the problem is severe in degree). The following scales were empirically derived by factor analysis: (1) irritability, agitation, crying (2) lethargy, social withdrawal (3) stereotypic behavior (4) hyperactivity, non-compliance and (5) inappropriate speech. To reduce the number of measures, this study used a composite score, labeled Problem Behavior composite. It is based on the mean Z score (mean = 0, SD = 1; calculated across the entire sample) across these five subscales.

Adaptive Functioning Level

Vineland Adaptive Behavior Scales Interview Edition (Vineland; Sparrow, Balla, & Cicchetti, 1984) is a widely used, standardized, caregiver interview designed to measure adaptive behavior in children from birth to 18 years 11 months. It consists of 297 items falling in four general domains of functioning; communication, daily living skills, socialization, and motor. The daily living skills domain was utilized for this study. This domain measures child skills in areas such as feeding, dressing, toileting, bathing and helping with household chores. Norms were derived from a national standardization sample of about 4,800 individuals with and without disabilities.

Results

Group differences in parenting stress and psychological function

The first analysis investigated whether mothers of children with ASD differed in terms of levels of parenting stress and psychological function (i.e., anxiety and depressive symptoms) as compared to mothers of developmentally delayed children. Using T-tests, we compared

mothers of children with ASD to mothers of children with developmental delays (Table 2). Mothers of children with ASD showed significantly higher Parenting Stress scores than the mothers of children in the DD group. Mothers of children with ASD also reported increased psychological distress, as measured by increased mean scores on the anxiety and depression scales of the BSI, compared with mothers of children in the DD group.

Group differences in child problem behavior and daily living skills

Children in the ASD group demonstrated higher levels of problem behavior ($n = 51$, $M = .51$, $SD = .82$.) compared with the children in the DD group ($n = 23$, $M = -.30$, $SD = .52$) as measured by the Problem Behavior composite score ($t(72) = 4.37$, $p < .001$). Children in the ASD group demonstrated lower Daily Living Skills scores ($n = 48$, $M = 60.17$, $SD = 8.85$) compared with the children in the DD group ($n = 21$, $M = 65.81$, $SD = 9.01$) as measured by the Vineland ($t(67) = -2.42$, $p < .05$).

Relationship between child characteristics and maternal parenting stress and psychological function

Using linear regression models, we sought to understand the degree to which measurements of child problem behavior and child daily living skills account for variability in mother's parenting stress and psychological distress. The child's diagnostic group was also included in the model to examine whether diagnostic group membership contributed to variability in parenting stress and psychological distress beyond these child variables. Finally, interaction terms (group by problem behavior, group by daily living skills) were included to test whether child variables differentially related to parenting stress and psychological distress as a function of diagnostic group. Results indicate that child problem behaviors were positively associated with both parenting stress and psychological distress (Table 3). Neither child diagnosis, nor child daily living skill was significantly related to parenting stress or mothers' psychological distress. Interestingly, the relationship between parenting stress and child problem behaviors did interact with diagnostic group (Std coeff (b) = .26, $t = 2.13$, $p < .05$). Parenting stress and child problem behaviors were more strongly correlated in the DD group (Pearson $r = .79$) than in the ASD group (Pearson $r = .45$).

Discussion

In this study, mothers of children with ASD reported higher mean levels of parenting stress and psychological distress than mothers of children in the DD group. Despite the fact that the two groups were matched on non verbal mental age at the outset of the study, children in the ASD group demonstrated lower daily living skills and higher problem behavior levels than children in the DD group. Child problem behavior was associated with elevations in parenting stress and psychological distress in mothers. No support was found for the contribution of impaired daily living skills or child diagnosis to increased parenting stress or psychological distress.

Thus, this study provides evidence that higher levels of child problem behaviors are significantly related to increased maternal parenting stress and psychological distress for both mothers of children with ASD and children with developmental delay without autism. This evidence is necessary, but not sufficient, to infer a causal relationship between parenting stress, psychological distress and child problem behavior. However, the findings are consistent with a theoretical model proposed by Hastings (2002). In this transactional model, child problem behavior drives parenting stress, which in turn disrupts parenting behavior, which then feeds back to increase child problem behaviors.

These findings call into question the hypothesis that difficulties in daily living skills demonstrated by children with developmental disabilities generally, and children with ASD in particular, are associated with increased parenting stress and psychological distress in mothers. It is somewhat anti-intuitive that the extra burden and day-to-day work involved with caring for children with decreased daily living skills is not associated with increased parenting related stress or psychological distress. These findings are supported by some previous research that found no significant relationship between adaptive functioning and stress in parents of children with developmental disabilities (Beck et al., 2004; Lecavalier, Leone, & Wiltz, 2006), but contradict other findings (Fitzgerald, Birkbeck, & Matthews, 2002; Tomanik, Harris, & Hawkins, 2004). At least in the preschool years, mothers appear to be resilient to the additional responsibilities that decreased daily living skills bring.

Although this study investigates psychological distress, we do not assume high scores on this measure represents maternal psychopathology. Coyne and Downey (1991) referred to the relationship between scores on self-report inventories and diagnosis of psychiatric disorders as “loose and complex”. It is important to interpret the results of this study in this light. That said, increased scores on symptoms related to parenting stress, anxiety and depressive symptoms warrant serious attention from clinicians and researchers. Elevations may be related to decreased parental quality of life and self-efficacy (Donenberg & Baker, 1993, Hastings & Brown, 2002, Rodrigue, Morgan, & Geffken, 1992). It has been proposed that elevations on these and similar scales may also be related to non optimal child development outcomes (e.g., Guralnick, 2006). Thus, psychological distress is relevant to those who aim to improve outcomes for parents as well as children with developmental disabilities.

These findings clarify prior research in two ways. First, limitations of prior research were overcome in the current study by the use of standardized diagnostic measures to assign group membership. Second, the use of a comparison group consisting of mothers with developmental-age matched children demonstrating developmental delay without autism, suggests that the higher demands placed on parents of children with disabilities can not alone account for increased stress in parents of children with autism.

Several cautions need to be considered when interpreting these findings. Participating families may be a unique subset of the population of families with children with disabilities. They are families with the time, energy and resources to participate in a longitudinal study of child development. Thus, this sample may not have adequately represented parents with the highest levels of parenting stress and challenges to their psychological functioning. Therefore, the findings here may not generalize to all segments of the larger population of families of children with disabilities. However, payment for participation, provision of diagnostic evaluation results at no-cost, and on-site child care may have allowed some families with higher stress to participate, partially ameliorating this concern.

This study examined the cross sectional relationship between child characteristics, parenting stress and maternal psychological distress. Longitudinal research is needed to clarify whether child problem behavior is causally related to parenting stress and psychological distress. Longitudinal research is also needed to understand developmental changes that may occur in the relationship between child characteristics, parenting stress and psychological distress. As one example, there may be important, predictable changes in child problem behavior that lead to increased or decreased parenting stress over the course of childhood.

Future research is also needed to develop a more complete model of factors that increase parenting stress and psychological distress. In particular the relation between problem behavior and parenting stress appears stronger in the DD group compared to the ASD group. This indicates there may be additional factors at play for mothers of children with ASD. A model

including SES, parental education, life events, spousal relationship quality, social support, and quality of education and intervention services for children is needed to better understand the range of factors that, in addition to child problem behavior and developmental level, may influence parents. Developmental transitions, such as school entry, may also be associated with positive or negative changes in parenting stress and psychological distress. Observational studies employing direct measures of parenting behavior are needed to assess such models and better understand the interrelationships between behavior, parenting stress and child problem behavior.

Specific intervention strategies can be best derived from identifying specific dimensions of child behavior that are most salient to parental distress (Gallagher & Bristol, 1989). This study suggests that problem behaviors are crucial targets of treatment in children with autism and children with developmental delay without autism. Targeting these behaviors may reduce parenting stress, improve psychological functioning, and ultimately increase the effectiveness of interventions designed to enhance child development.

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Table 1

Sample characteristics for ASD and DD groups

Variable	ASD N=51 Mean (SD)	DD N=23 Mean (SD)	Test statistic	p
Child				
Age (months)	43.88 (4.26)	43.74 (4.79)	t(71) = .126	ns
Gender(%male)	88%	61%	$\chi^2(1)=7.35$	<.01
Race(%Caucasian)	70%	64%	$\chi^2(1)=0.24$	ns
Non Verbal Mental Age	28.46 (7.65)	30.15 (9.35)	t(71) = -0.82	ns
Vineland ABC Std Score	60.5 (9.3)	63.8 (7.4)	t(66) = -1.45	ns
Parent				
Mother's age	35.99 (5.29)	36.30 (4.45)	t(70) = -0.24	ns
Maternal Ed.				
No College	20%	26%	$\chi^2(2)=1.42$	ns
Some College	26%	35%		
Completed College	54%	39%		
Number of siblings	1.14 (0.94)	1.48 (1.16)	t(72) = -1.34	ns
Avg age of siblings (yrs)	5.22 (3.24)	6.10 (3.99)	t(68) = -0.96	ns
Family SES	47.67 (11.35)	46.54 (13.49)	t(69) = 0.37	ns
Negative Life Changes	7.69(7.52)	5.04(5.99)	t(72) = 1.48	ns

Table 2

Maternal parenting stress and psychological distress by diagnostic group

	ASD		DD		t
	M	SD	M	SD	
Parenting Stress ^a	2.30	.35	2.03	.36	23 3.05**
Psych Distress ^b	.64	.57	.34	.47	23 2.13*

* p<.05,

** p < .01

^a scores range from 1 to 4

^b scores range from 0 to 4

Regression results for parenting stress and psychological distress including diagnostic group, problem behavior, daily living skills and interaction by group

Table 3

	Parenting Stress		Psych Distress	
	Std Coeff (β)	t	Std Coeff (β)	t
R ²	.437		.216	
Group (ASD=0, DD=1)	-.56	-.78	-1.06	-1.26
Problem Behavior	.47	3.71***	.40	2.76**
Daily Living Skills	-.08	-0.58	-.001	-0.01
Group X Problem Behavior	.25	2.16*	-.02	.18
Group X Daily Living Skills	.57	0.78	1.02	1.18

* $p < .05$,

** $p < .01$,

*** $p < .001$