

Parenting stress in caregivers of young children with concerns about ASD prior to a formal
diagnostic evaluation

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A thesis

submitted in partial fulfillment of the
requirements for the degree of

Master of Science

University of Washington

2019

Committee:

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Program Authorized to Offer Degree:

Psychology

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Abstract

Parenting stress in caregivers of young children with concerns about ASD prior to a formal
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Robust findings demonstrate that parents of children with autism spectrum disorder (ASD) experience high levels of parenting stress that are related to negative outcomes for families. Although the majority of research on parenting stress has focused on parents of children with a current ASD diagnosis, parents of young children with concerns about ASD-related behaviors also face many unique challenges before the child receives a formal ASD diagnostic evaluation. However, no study to date has examined patterns of parenting stress among parents of children with ASD concerns prior to a formal ASD diagnosis. Therefore, the current study investigated longitudinal trajectories of parenting stress among parents of young children with ASD concerns compared to parents of children with non-ASD developmental concerns (e.g.,

language delay), and parents of children with no developmental concerns. Known predictors of parenting stress were also examined. Results revealed that parents of children with ASD concerns experienced consistently higher levels of parenting stress across early child development compared to parents of children with non-ASD developmental concerns and children with no concerns. Additionally, parenting efficacy, parent psychological functioning, parent social quality of life, and child social communication behaviors predicted levels of parenting stress for all parents.

Introduction

Parenting stress is a specific form of stress arising from parenting-related challenges and a relative lack of perceived resources to adapt to the demands of those challenges (Deater-Deckard, 1998, 2004). Models of parenting stress suggest that the amount of stress experienced in the caregiving role is strongly influenced by characteristics of the parent (e.g., psychological well-being), characteristics of the child (e.g., behavior problems), and the degree of conflict within the parent-child relationship (Abidin, 1990; 2012; Deater-Deckard, 2004). Given many different factors that may impact the parent-child relationship across development, parenting stress fluctuates over time and can result in bi-directional effects between parenting stress and child outcomes. (Abidin, 1990; Deater-Deckard, 1998, 2004; Neece, Green, & Baker, 2012). For example, parenting stress and child externalizing behavior problems have been shown to covary across child development such that greater parenting stress predicts greater child externalizing problems and vice versa (Neece et al., 2012). Elevated parenting stress also contributes to multiple negative outcomes for caregivers such as poorer physical health and higher rates of anxiety and depression (Deater-Deckard, 1998, 2004). Such findings have motivated continued efforts to understand risk factors for parenting stress. Although many such factors have been identified, previous work suggests that challenges associated with caring for a child with a medical condition or developmental disability are strongly related to higher levels of parenting stress (Deater-Deckard, 2004; Hanson & Hanline, 1990; Hauser-Cram et al., 2001; Hayes & Watson, 2013; Tervo, 2012).

In particular, robust findings demonstrate that parents of children diagnosed with autism spectrum disorder (ASD) report high levels of parenting stress, and experience more

parenting stress compared to parents of children with typical development and parents of children with other developmental disorders (for a review, see Hayes & Watson, 2013). ASD is a neurodevelopmental disorder characterized by deficits in social communication and interaction as well as repeated and repetitive behaviors and interests. Given these core symptoms, parents of children on the autism spectrum are likely to experience unique challenges associated with interacting and bonding with their child, clearly understanding their child's needs, managing challenging behaviors, and caring for their child's well-being. Indeed, multiple studies report associations between parenting stress and core ASD symptoms (Davis & Carter, 2008; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005; Kasari et al., 1997; Rodriguez, Hartley, & Bolt, 2019). For example, in a study among parents of toddlers with an ASD diagnosis, Davis and Carter (2008) found that lower levels of child social relatedness were associated with increased parent-child relationship problems and higher levels of parenting stress.

Additionally, parents of children with ASD often face stressors associated with medical and psychiatric conditions that commonly co-occur with ASD. Previous work suggests that cognitive impairment, lower adaptive functioning, and behavior problems contribute to both parenting stress (Bebko, Konstantareas, & Springer, 1987; Estes et al., 2009; Hall & Graff, 2011; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013) and reduced parent well-being (Salomone et al., 2018). Moreover, both core and associated symptoms of ASD frequently require specialized services. Although these services are focused on improving child behavior and outcomes, some evidence suggests that having a child with ASD who requires special needs services is associated with elevated parenting stress (Schieve, Blumberg, Rice, Visser, & Boyle,

2007). However, it is unclear whether this finding is due to characteristics of the child, the demands associated with pursuing services, or both.

For parents of children with ASD, parenting stress is associated with higher rates of parent psychopathology (Charman et al., 2016; Phetrasuwan & Shandor Miles, 2009; Salomone et al., 2018; Singer, 2006), and increased strain on family relations including higher rates of divorce (Hartley et al., 2010). Moreover, among families of children with ASD there is a transactional relationship between parenting stress and negative outcomes over time. For example, in a recent longitudinal study among families of school-aged children with ASD, Rodriguez et al. (2019) found that parenting stress predicted child internalizing and externalizing problems and, in turn, child externalizing problems predicted later parenting stress, particularly among fathers. Additionally, a reciprocal relationship between ASD symptoms and parenting stress was found, such that ASD symptoms led to increased parenting stress, which in turn predicted later increases in ASD symptom severity among children. Finally, parenting stress can negatively impact the effectiveness of interventions for children with ASD. Osborne, McHugh, Saunders, and Reed (2008) found that parenting stress was associated with reduced effectiveness of an early teaching intervention for ASD. Similarly, parenting stress was associated with poorer child outcomes after an ASD-tailored treatment for co-occurring psychopathology (Weiss, Vecili, & Bohr, 2015). Given the unique factors related to ASD that contribute to parenting stress, and the negative impact of parenting stress on family well-being, continued investigation of parenting stress within the context of the ASD phenotype is crucial to efforts to improve parent and child outcomes (Hayes & Watson, 2013; Nordahl-Hansen, Hart, & Øien, 2018).

The extant literature on parenting stress in the context of ASD has primarily focused on families of children with an ASD diagnosis. While this has and continues to be critical work, the types of challenges that families of children with ASD face are not solely born out of a diagnostic label. Rather, ASD-related challenges that impact caregivers begin to emerge early in child development, long before the child has received an ASD diagnostic evaluation. For example, previous work demonstrates that parents commonly express concerns about their child's ASD-related behaviors around 18-months-of age (Coonrod & Stone, 2004), years before the median age of ASD diagnosis [i.e., 4.33 years (Baio et al., 2018)]. Given that core ASD behaviors are correlated with parenting stress among families of children with a diagnosis, the presence of undiagnosed ASD-related behaviors in early development may also affect the parent's perceived ability to connect with and care for their child, and could result in heightened parenting stress.

Parents of children with ASD concerns also face a myriad of challenges related to the surveillance and care of their child during the window of time prior to receiving a diagnostic evaluation (Carbone et al., 2013; Mulligan, MacCulloch, Good, & Nicholas, 2012; Zuckerman, Lindly, & Sinche, 2015). Parents who express early concerns about ASD to their child's health care provider are more likely to receive passive responses from the provider compared to parents with other developmental concerns (Zuckerman et al., 2015). Parents also experience higher levels of parenting stress when they perceive less collaboration with health care providers (Moh & Magiati, 2012). Then, even after families do receive a referral for an evaluation, parents report a long delay before receiving diagnostic services that coincides with a worry-laden period of time that is intensely difficult (Mulligan et al., 2012).

Although it is clear that parents of children with ASD concerns do face many unique challenges associated with their caregiving role, parenting stress has not been specifically investigated among ASD-concerned parents before their child receives diagnostic confirmation. Therefore, the present study used a prospective, longitudinal design to characterize experiences of parenting stress among a community sample of parents of children with ASD concerns across their child's early development. Our primary aim was to investigate patterns of parenting stress among parents of young children with ASD concerns compared to parents of children with non-ASD developmental concerns (e.g., language delay) and parents of children with no developmental concerns. Previous work demonstrates that parents of children with an ASD diagnosis report higher levels of parenting stress compared to parents of children with other disabilities and parents of children with typical development (Hayes & Watson, 2013). However, since children demonstrate ASD-related behaviors long before receiving a diagnosis (Coonrod & Stone, 2004) and parents face many unique challenges during this intervening period (Mulligan et al., 2012; Zuckerman et al., 2015), ASD-concerned parents likely experience elevated levels of parenting stress as well. Therefore, we predicted that parents of children with ASD concerns would show higher levels of parenting stress across time compared to parents of children with non-ASD developmental concerns and parents of children of typical development.

Work is also needed to assess the impact of ASD concerns on parenting stress within the context of other factors to determine if ASD concerns contribute uniquely to parenting stress above and beyond previously identified predictors of parenting stress (Hayes & Watson, 2013). Therefore, for our secondary aim, we examined parenting efficacy, parent psychological

functioning, parent social quality of life, and child social communication behaviors as predictors of parenting stress because these have been associated with parenting stress (e.g., Davis & Carter, 2008; Deater-Deckard, 1998, 2004). We predicted that lower levels of parenting efficacy, psychological functioning, social quality of life, and child social communication behaviors would predict higher levels of parenting stress. Additionally, we hypothesized that having a child with ASD concerns would contribute to parenting stress above and beyond these parent and child predictors.

Method

Participants

Participants in the present study were recruited as part of a larger, community-based project aimed at implementing universal early screening for ASD in primary care practices during 18-month well-child visits and expediting access to ASD-specific early intervention for children with ASD concerns before they receive a formal diagnostic evaluation. Families were recruited from participating primary care providers (PCPs) and early intervention (EI) providers in four counties in Washington State: Spokane, Yakima, Skagit, and Lewis counties. For the larger study, two separate family cohorts were recruited: one before the community intervention was introduced and the other after PCPs and EI providers received specialized training. Families recruited through their child's PCP were eligible to enroll in the study if their child was between 16 to 20 months old at the time of enrollment, to assess family experiences with PCPs during and after 18-month well child visit. Families recruited through their child's EI provider were eligible to enroll in the study if their child was between 16 to 36 months old at the time of enrollment, to assess family experiences with early intervention services. Although

all families met these inclusion criteria at the time of enrollment, some families completed the first wave of data collection after their child was older than the age ranges specified above (e.g., 42-months-old). Families were excluded from participating if their child had a severe medical condition or they were not referred from a participating PCP practice or EI agency. The present study only included data from families who were enrolled prior to the specialized training intervention for PCPs and EI providers. Additionally, families were only included in the present study if they provided sufficient data (described below) and the child had not received an ASD diagnostic evaluation at the beginning of the study. Over the course of the study, 4 families reported to the study team that their child received a confirmed ASD diagnosis (see Discussion).

Parents interested in participating in the study completed a “permission to contact” form and were contacted by trained research staff to determine their eligibility. The research staff conducted a structured interview with parents to identify their specific concerns about their child’s development. Specifically, parents were asked if they had explicit concerns about ASD or social development as well as concerns about language, motor, sensory, and behavioral challenges. Algorithms were used to assign parents to the appropriate “concerns” group based on the types of concerns parents endorsed. Two trained members of the study staff confirmed group assignment and any discrepancies were reconciled by senior research staff.

A total of 281 parent-child dyads were included in this study. Parents were assigned to the ASD concerns group if they endorsed explicit concerns about ASD or reported concerns about social interaction combined with the presence of at least one of the following behaviors: unusual use of language or vocalization (e.g. unusual intonation), language delay, unusual use

of toys or objects (e.g. lining up toys), unusual body movements (e.g., hand flapping), and/or hyper- or hypo-sensitivity to sensory experiences. Parents were assigned to the non-ASD developmental concerns group if they endorsed developmental concerns related to language, motor, sensory, social, and/or behavioral problems, but did not endorse a combination of concerns that met criteria for the ASD concerns group described above. Finally, parents were assigned to the no concerns group if they did not endorse any developmental concerns for their child. The current study included 46 parents of children with ASD concerns, 62 parents of children with non-ASD developmental concerns, and 173 parents of children with no developmental concerns. Among the ASD concerns group, all 46 parents included in the present study reported explicit concerns about ASD. Among the non-ASD developmental concerns group, 53 parents reported language concerns, 18 parents reported motor concerns, 9 parents reported social concerns (without the presence of another behavioral concern required for the ASD concerns group), 4 parents reported sensory concerns, and 18 parents reported other types of behavioral concerns (e.g., tantrums or dysregulation). Of these concern categories, 85% of parents in the non-ASD developmental concerns group reported concerns in two categories, 9.7% reported concerns in three categories, and 4.8% of parents reported concerns in four categories.

Sample characteristics are presented in Table 1. Differences between the three concern groups were observed for child age, $F(2, 278) = 49.50, p < .001$, the ratio of male to female children (Fisher's Exact Test, $p = .02$), and referral source (PCP or EI; Fisher's Exact Test, $p < .001$). There were no group differences for caregiver age, caregiver race (white vs nonwhite),

caregiver education (no college vs. college), the ratio of maternal to paternal caregivers, or child race (ps range: .08 - .62).

Table 1 Sample Demographics

	ASD Concerns	Non-ASD Developmental Concerns	No Concerns
	$n = 46$	$n = 62$	$n = 173$
Caregiver			
Age in years [M (SD), Range]	33.84 (8.27), 21.25-58.25	33.74 (4.93), 25.58-51.33	32.35 (5.11), 17.67-46.92
Gender [Female: n (%)]	44 (95.65)	61 (98.39)	159 (91.91)
Race [Non-white: n (%)]	6 (13.04)	8 (12.90)	9 (5.20)
Education [No College: n (%)]	12 (26.09)	13 (20.96)	34 (19.65)
Child			
Age in months [M , (SD), Range]	26.15 (5.61), 17-42	23.71 (0.67), 17-34	20.68 (1.61), 18-31
Gender [Female: n (%)]	17 (36.96)	21 (33.97)	89 (51.11)
Race [Non-white: n (%)]	10 (21.74)	9 (14.52)	17 (9.83)
Referral Source			
PCP [n , (%)]	16 (34.78)	34 (54.84)	172 (99.42)
EI Provider [n , (%)]	30 (65.22)	28 (45.16)	1 (0.58)

Procedure

All study procedures were approved by the University of Washington institutional review board. All participating families provided written consent prior to the initiation of study activities.

Upon enrollment to the larger community-based study, parents were sent a battery of nine questionnaires to complete, five of which were used to address the aims of the present study. Questionnaires were completed online using a REDCap (Harris et al., 2009) interface, and were also available in paper versions upon request. For participants whose primary language was Spanish, all questionnaires were translated into Spanish. Six families in the present study reported Spanish as their primary language. All parents were additionally asked to complete the

same battery of questionnaires at approximately 3- and 6-months after they completed the initial wave of data collection, which yielded three waves of data in total. Participant in the present study provided data for all predictors at wave 1 and provided parenting stress data at least one of the three waves (See Table 2). Parents who only provided parenting stress data for wave 1 did not differ on parenting stress or any predictor at wave 1 compared to parents who completed multiple waves (ps range: .23 - .87). Additionally, there were no group differences for parents who provided parenting stress data at wave 1 only compared to parents who provided parenting stress data for multiple waves (Fisher's Exact Test, $p = .17$).

Measures

Parenting Stress Index-Short Form: The Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995), a widely used measure of parenting stress, is a 36-item self-report measure that assesses stress arising from characteristics of the parent, child, and parent-child relationship. All items are rated on a 1 (Strongly Agree) to 5 (Strongly Disagree) scale. The PSI-SF comprises 3 subscales: parent distress, difficult child, and parent-child dysfunctional interaction. Although the PSI-SF has been widely used to assess parenting stress in the context of ASD, evidence suggests that some items from individual subscales may not clearly discriminate parents across a range of stress severity (Zaidman-zait et al., 2010). Therefore, the current study only analyzed the PSI-SF total stress score. Total stress scores range from 36-180 and higher scores indicate more parenting stress. Scores for missing items were imputed according to Abidin (1995). To model parenting stress across time, total scores of parenting stress for all three waves were used in analysis.

Parenting Efficacy Scale: The Parenting Efficacy Scale (PES; Teti & Gelfand, 1991) is a 10-item questionnaire that assesses self-perceived parenting efficacy across various domains of parenting a young child (e.g., soothing the child when the child is upset, getting the child to pay attention to the parent, knowing what the child enjoys). All items are rated on a 1 (Not Good At All) to 4 (Very Good) scale. The PES has strong internal and concurrent validity (Teti & Gelfand, 1991), and has been used previously to assess self-reported parenting efficacy among parents of children with ASD (Kuhn & Carter, 2006). Data were considered complete if no more than 1 item was missing. To account for any missing items, mean scores were calculated for each participant. Higher scores indicate greater self-reported parenting efficacy. Data from wave 1 were used for analysis.

World Health Organization Quality of Life Assessment-BREF: The WHOQOL-BREF (WHOQOL Group, 1998) is a 26-item survey that assesses perceived health satisfaction across 4 domains of life: psychological, physical, social, and environment. All items are rated on a 1 to 5 scale. The WHOQOL has been validated across different populations, including parents of children with ASD (Dardas & Ahmad, 2014). Based on an *a priori* aim to focus on psychological functioning and social quality of life in the present study, only the psychological and social domains were analyzed. The psychological domain consists of 6 items such as “How often do you have negative feelings such as blue mood, despair, anxiety, depression?” The social domain consists of 3 items such as “How satisfied are you with the support you get from your friends?” These two domains have shown strong reliability (α 's > .89 (WHOQOL Group., 1998). Data were considered complete if no more than 1 item was missing from each domain. To account for any missing items, mean scores for both domains were calculated for each

participant. Higher scores indicate greater psychological functioning and social quality of life. Data from wave 1 were used for analysis.

Parent Interview for Autism-Clinical Version: The Parent Interview for Autism–Clinical Version (PIA-CV; Stone et al., 2003) is a parent-report questionnaire developed to assess ASD symptom severity in young children. It comprises 11 behavioral domains, and has been used previously with children under 24 months (Carter et al., 2011). Domain scores on the PIA-CV have demonstrated sensitivity to differences between diagnostic groups, to change over time, and to intervention effects (Carter et al., 2011; Ibanez et al., 2018; Stone et al., 2003). Four domains of social communication behavior were used in the present study: social relating, imitation, language understanding, and nonverbal communication. These 4 domains comprised 41 items rated on a 1 to 5 scale. Items were reverse scored as needed. Data were considered complete if no more than 1 item was missing from each domain. To account for any missing items, mean domain scores were calculated. Then mean domain scores were combined to create a mean social communication score for each participant. Higher scores indicate more developmentally appropriate social communication behaviors. Data from wave 1 were used for analysis.

Table 2 Descriptive Statistics

		ASD Concerns	Non-ASD Developmental Concerns	No Concerns
	Wave	<i>M</i> (<i>SD</i>) Range	<i>M</i> (<i>SD</i>) Range	<i>M</i> (<i>SD</i>) Range
PSI-SF	1	<i>n</i> = 46 92.67 (24.20) 40-163	<i>n</i> = 62 65.50 (23.68) 38-148	<i>n</i> = 173 57.35 (18.85) 36-170
	2	<i>n</i> = 35 93.89 (30.05) 39-177	<i>n</i> = 54 64.98 (23.69) 40-129	<i>n</i> = 149 60.19 (20.03) 36-169
	3	<i>n</i> = 26 86.42 (24.51) 42-129	<i>n</i> = 39 62.41 (22.51) 40-127	<i>n</i> = 118 60.60 (22.99) 36-165

PES	1	2.99 (0.47) 2.0-3.8	3.32 (0.43) 2.0-3.9	3.52 (0.29) 2.8-4.0
WHOQOL Social	1	3.18 (1.03) 1.0-5.0	3.80 (0.82) 1.0-5.0	4.01 (0.72) 1.3-5.0
WHOQOL Psychological	1	3.39 (0.78) 1.7-5.0	3.74 (0.10) 1.0-5.0	3.88 (0.60) 1.6-5.0
PIA-CV	1	2.96 (0.58) 1.9-4.2	3.42 (0.48) 2.1-4.2	3.77 (0.32) 2.4-4.6

PSI-SF: Parenting Stress Index-Short Form; PES: Parenting Efficacy Scale; WHOQOL : World Health Organization Quality of Life Assessment; PIA-CV: Parent Interview for Autism-Clinical Version.

Analytic Approach

All analyses were performed using SPSS Mixed function. Parenting Stress (PSI Total Score) levels and trajectories were estimated using multilevel modeling (MLM) to account for observations nested within individuals over time, unbalanced data, and missing data (Hoffman, 2015). All model parameters were estimated using Maximum Likelihood Estimation. Time was modeled using child age centered at 17 months of age, the youngest age in the sample. Initial modeling was conducted to determine the best fitting model for time. A within-person empty model yielded an interclass correlation (ICC; Hoffman, 2015) indicating that 74% of the original variance in parenting stress was due to between-person differences in the intercept (ICC = 0.74). Due to between- and within-person variability, the best fitting Level-1 model for time included a random intercept and a random linear slope. The ASD concerns group was entered as the reference group (ASD concerns = 0) in order to examine patterns of parenting stress among ASD-concerned parents compared to the other two concern groups. All predictors were centered to their own grand means. Two final models were estimated to directly test the aims of the present study.

Results

Descriptive statistics are presented in Table 2. One-way ANOVAs indicated that all four predictors differed significantly across concern groups: PES, $F(2, 278) = 41.21, p < .001$; WHOQOL Psychological, $F(2,278) = 10.04, p < .001$; WHOQOL Social, $F(2, 278) = 19.35, p < .001$; PIA-CV, $F(2, 279) = 74.12, p < .001$. Bonferroni-corrected comparisons revealed that the ASD concerns group reported lower parenting efficacy, lower psychological functioning, lower social quality of life and lower child social communication behaviors compared to both the non-ASD development concerns group and the group with no developmental concerns ($ps < .05$).

As shown in Table 3 (column 1), Model 1 tested the effect of concern type on levels and slopes of parenting stress. A significant fixed effect of concern type indicated that parents of children with ASD concerns reported higher levels of parenting stress at the intercept compared to parents of children with non-ASD developmental concerns and parents of children with no developmental concerns. The (concern type X age) interaction was nonsignificant, suggesting that levels of parenting stress among parents of children with ASD concerns remained consistently higher across time. To test whether gender differences affected parenting stress, child gender was entered into the model, but was not a significant predictor of parenting stress ($p > .05$). As such, this parameter was removed from the final models.

Table 3 Parenting Stress: Final Model Results

Estimated Parameters	Model 1	Model 2
	<i>B (SE)</i>	<i>B (SE)</i>
Intercept	91.70 (4.88)**	96.34 (7.64)**
Age (Linear)	0.10 (0.39)	0.08 (0.64)
Child Concerns (ASD concerns = 0)		
No Concerns	-35.58 (5.23)**	-10.07 (4.78)*
Non-ASD Developmental	-28.80 (6.00)**	-11.15 (4.91)*
Child Concerns x Age (ASD concerns = 0)		

No Concerns	0.36 (0.45)	0.41 (0.73)
Non-ASD Developmental	0.16 (0.50)	0.07 (0.85)
Parenting Efficacy	-	-18.29 (3.96)**
Psychological Functioning	-	-8.44 (2.28)**
Social Support	-	-6.33 (1.83)**
Child Social Communication	-	-7.90 (3.00)**
<hr/>		
Model Fit		
-2LL	6050.98	6.058.63
AIC	6070.98	6086.63
BIC	6116.52	6150.38

* $p < .05$, ** $p < .01$

Model 2 tested the effects of the four parent and child predictors on parenting stress. Since an effect of time was not observed in Model 1, Model 2 tested fixed effects of predictors on levels of parenting stress only. As shown in Table 3 (column 2), lower levels of parenting efficacy, parent psychological functioning, parent social quality of life, and child social communication behaviors significantly predicted higher levels of parenting stress ($ps < .01$). Within MLM, model fit can be assessed by observing change in fit indices when more parameters (e.g. predictors) are added to a model within a nested structure (Hoffman, 2015). Specifically, if the addition of more parameters leads to a reduction in fit indices (e.g., -2LL) model fit is improved. Although parenting efficacy, psychological functioning, social quality of life, and child social communication behaviors were significant when entered as fixed effects in Model 2, the addition of these four predictors did not result in improvement to estimated model fit as shown by a lack of reduction in fit indices compared to Model 1. However, these predictors were retained and reported because 1) we made an *a priori* decision to investigate the contribution of these factors to parenting stress within our sample and 2) previous work demonstrates a meaningful association between these factors and parenting stress (Davis & Carter, 2008; Deater-Deckard, 1998, 2004).

Discussion

The present study is the first longitudinal investigation of parenting stress among parents of young children with ASD concerns prior to receiving a diagnostic evaluation. The results indicate that ASD-concerned parents experience significantly higher levels of parenting stress across their child's early development compared to parents of children with non-ASD developmental concerns and parents of children with no concerns. This finding is consistent with a recent meta-analysis showing higher levels of parenting stress among parents of children with an ASD diagnosis compared to parents of children with other developmental disorders and parents of children with typical development (Hayes & Watson, 2013), suggesting that ASD-related behaviors influence higher levels of parenting stress in early development *before* the child receives a formal diagnostic evaluation. For example, ASD-related behaviors such as weaker social communication likely interfere with the parent's perceived ability to connect with their child, which may lead to strain on the parent-child relationship and contribute to parenting stress (Abidin, 1990). Indeed, we observed that weaker social communication behaviors predicted greater parenting stress in the overall sample, and mean social communication behaviors were lower for children with ASD concerns. These findings are consistent with previous studies showing a relationship between social communication challenges and parenting stress (Davis & Carter, 2008; Kasari et al., 1997), and were expected results given that social communication challenges constitute core ASD diagnostic criteria. Some studies that have included parents of older children and adolescents with ASD have not found associations between parenting stress and core ASD symptoms per se (McStay et al., 2013; Salomone et al., 2018). It may be the case that developmental factors interact with

parenting stress and ASD symptoms such as impaired social communication. For example, some have proposed that adaptive behavior problems may become more challenging for parents as children get older (Salomone et al., 2018). Thus, parents of older children with ASD may struggle more with managing co-occurring behavioral issues than the parents of young children with ASD concerns studied here.

Although weaker social communication behaviors are one reason for concerns about ASD, it is important to note that having ASD concerns continued to significantly predict parenting stress after child social communication behaviors (and other predictors) were entered into Model 2. This suggests that there may be other factors associated with ASD concerns that affect parenting stress above and beyond child social communication behaviors. For example, other ASD symptoms such as repetitive behaviors or sensory sensitivities may introduce additional challenges for families that contribute to parenting stress. Moreover, the commonly reported obstacles parents face when they seek appropriate assessment of their child's concerning behaviors and wait for a definitive diagnostic decision likely contribute to parenting stress as well (Mulligan et al., 2012; Zuckerman et al., 2015). Future work should focus on delineating how different factors associated with having ASD concerns contribute uniquely to parenting stress.

The present study also analyzed parent psychological functioning, social support, and parenting efficacy to better understand the contribution of ASD concerns within the context of these previously reported predictors of parenting stress. Consistent with previous work, we found that higher levels of psychological functioning, social support, and parenting efficacy predicted lower levels of parenting stress. Although these factors, along with child social

communication behaviors, did not improve estimated model fit, they were significant predictors of parenting stress among all parents in our sample. Given that these factors have been previously associated with parenting stress (e.g., Davis & Carter, 2008; Deater-Deckard, 1998, 2004), we view these predictors as meaningful parent and child-related factors that should be considered in models of parenting stress among parents of children with ASD concerns, other types of developmental concerns, and typical development. Importantly, since the current findings align with previous work, our results add further evidence that intervention strategies that target these factors (e.g., parent training programs for improving parenting efficacy) may reduce parenting stress. However, since these factors were associated with parenting stress among all parents in our sample, future work is needed to determine how these factors impact families of children with ASD concerns specifically. Additionally, it is possible that these predictors have a bi-directional relationship with parenting stress. Thus, future studies with access to sufficient timeseries data for parenting stress and predictors of parenting stress could use time-varying multilevel modeling or cross-lagged modeling procedures to determine the strength and direction of these relationships. Finally, modeling how these predictors interact and relate to other parent and child outcomes among families of children with ASD concerns may provide a more integrated picture of factors contributing family well-being.

Although this study provides clear evidence that parents of children with ASD concerns experience high levels of parenting stress, there are some limitations to note. First, we were not able to compare parenting stress between maternal and paternal caregivers due to the low number of paternal caregivers in our sample. Previous work suggests that patterns and

predictors of parenting stress might differ between mothers and fathers, or between male and female caregivers (Davis & Carter, 2008; Deater-Deckard, 2004; Rodriguez et al., 2019). Future work should seek to compare parenting stress among male and female caregivers of children with ASD concerns to identify differences that could inform tailored interventions for parenting stress. Second, future studies should assess other child and family characteristics. For example, child externalizing behavior problems were not measured in the present study, but are a well-known predictor of parenting stress (Deater-Deckard, 2004). Third, the present study did not investigate how demographic factors such as family socioeconomic or majority/minority status might influence parenting stress. Previous work suggests that these factors are associated with parenting stress and parenting behavior (Emmen, Malda, Mesman, Ijzendoorn, & Prevo, 2013); future work should assess the impact of demographic factors on parenting stress among parents of children with ASD concerns. Fourth, the present study modeled parenting stress over a relatively short time period in early child development. Our knowledge of parenting stress among parents of children with ASD concerns will benefit from studies that are able to examine parenting stress at multiple timepoints across a wider period of early child development. Finally, over the course of the study we became aware that four children in the ASD concerns group received a diagnosis of ASD after the first wave of data collection because their parents sent diagnostic reports to the study team. Of note, this was not part of the original study design. Specifically, the present study was drawn from a larger project focused on community implementation of early screening tools and ASD-specific early interventions for children prior to diagnostic evaluation. Due to the community-based nature of this project, the study team did not have direct contact with families (i.e., participants did not come into the lab) and

therefore did not have a systematic way to assess diagnostic status (e.g., using gold-standard diagnostic methods). We chose to include data from these four families in the present study because they met the inclusion criteria at the beginning of the study. Specifically, all four children did not have an ASD diagnosis before the first wave of data collection. It is possible that the experiences of these four families changed in some way after receiving a diagnosis (i.e., after wave 1). However, closer inspection of these families revealed patterns of parenting stress that align with the present findings that ASD-concerned parents had higher levels of parenting stress at wave 1 that remained consistently high (i.e., stable) over time. Moreover, the present findings are consistent with a recent meta-analysis by Hayes and Watson (2013) showing that parents of children with an ASD diagnosis experience more parenting stress compared to parents of children with other developmental disorders and parents of children with typical development. Thus, there may be continuity between the experience of parenting stress before and after a child receives an ASD diagnosis. Future studies, with larger samples and systematic methods for assessing diagnostic outcomes, should investigate whether patterns of parenting stress differ for parents of children who will go on to receive a diagnosis compared to those who do not receive a diagnosis.

Despite these limitations, the current study has important implications for improving strategies to help and support families of children with ASD concerns during a worry-laden time in early child development. First, since parents of children with ASD concerns experience high levels of parenting stress across time, more work is needed to develop and test interventions to determine effective ways to help parents cope with unique stressors. Recent work suggests that parents of children with an ASD diagnosis benefit from cognitive behavior therapy

(Maughan & Weiss, 2017), Acceptance and Commitment Therapy (Blackledge & Hayes, 2006), and Mindfulness Based Stress Reduction (Bazzano et al., 2015; Ferraioli & Harris, 2013). Future work should study the effectiveness of evidence-based psychotherapies for improving psychological functioning and decreasing parenting stress for parents of children with ASD concerns. Second, due to long delays accessing diagnostic services and other obstacles parents face to assess the development of their young child (Mulligan et al., 2012; Zuckerman et al., 2015), efforts are emerging to implement ASD-specific early interventions for young children with ASD concerns before they receive a diagnostic evaluation to expedite access to treatment services during a critical period of early development. However, previous research suggests that high levels of parenting stress have been shown to reduce the effectiveness of ASD-specific interventions (Osborne et al., 2008; Weiss et al., 2015). Therefore, efforts to implement early interventions for young children with ASD concerns prior to formal diagnostic evaluation should consider the high levels of parenting stress experienced by their parents and possible effects on child treatment response.

Parents of children with ASD concerns experience overwhelming worry and multifaceted challenges while caring for their child prior to a formal diagnostic evaluation. The present study demonstrated that these parents experience significantly higher levels of parenting stress across time compared to parents of children with non-ASD developmental concerns and parents of children with no concerns. These findings are consistent with studies of parenting stress among parents of children with an ASD diagnosis (Hayes & Watson, 2013) suggesting that there may be continuity in the experience of parenting stress before and after a diagnosis is given. Critically, the present findings highlight the need to develop and implement

interventions to help and support ASD-concerned parents early in their child's development.

Given the negative effects of parenting stress on families, a family-centered approach to research and intervention that considers the interaction between parent and child well-being will best inform current efforts to promote better outcomes.

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