

Preliminary characterization of parent-child interaction in preschoolers with Prader-Willi  
Syndrome: The relationship between engagement and parental stress

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### Abstract

Early parent-child interactions (PCI) impact social cognitive development. Relatedly, children with various developmental disorders exhibit abnormal parental attachment relationships. Parental characteristics and behaviors can impact PCI and socioemotional development as well. No research has examined the parent-child dynamic in Prader-Willi Syndrome (PWS), a neurodevelopmental disorder which presents with social cognitive deficits. This paper provides a preliminary characterization of PCI quality and parenting stress in 17 PWS parent-child dyads, children ages 3-5 years, in comparison to 20 typically developing children and their parent. Results suggest early PCI disruption in preschoolers with PWS and their parents report increased levels of stress in various domains. These findings have important implications not only on parent well-being in PWS but its impact on child development.

**Keywords:** Prader-Willi Syndrome, parent-child interaction, parenting stress

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Early parent-child interactions strongly impact the development of skills relating to social cognition (Leclère et al., 2014; Olson & Dweck, 2008). A parent's ability to show coordinated joint engagement during early interactions with their preschool-aged child relates to higher sociability and adaptive functioning later on in life (Adamson, Bakeman, Deckner, & Nelson, 2012; Haven et al., 2013). Recent research provides initial support for the notion that these early parent-child interactions not only shape behavior but also biological mechanisms that relate to stress and social engagement (Carter, 2014; Feldman et al., 2013).

The development of early parent-child relationships and its disruption may relate to social cognitive deficits (Leclère et al., 2014; Olson & Dweck, 2008). Research suggests that many young children with autism spectrum disorder (ASD) exhibit abnormal parental or caregiver attachment interactions (Adamson et al., 2012; Williams, 2003). For example, Adamson et al. (2012) measured engagement across parent-child dyads with ASD, Down's syndrome (DS), or typical development (TD) during a joint play task. Results indicated that coordinated joint engagement, defined as the child's ability to attend to both the play objects and the play partner during the task, was significantly less likely in children with ASD (Adamson et al., 2012). These findings are consistent with previous research in showing that during face to face interactions, toddlers diagnosed with ASD are significantly less likely than TD children to make eye contact, use joint attention, engage in social turn-taking, imitate gestures or communication, and anticipate social routines during play sessions with a parent or caregiver (Bernebei et al., 1998; Dawson et al., 1990; Gillberg et al., 1990; Williams, 2003). The potential inability children with ASD have in evidencing these behaviors makes it difficult for parents to engage with them in a

meaningful way during day to day activities. Research has also shown that lack of eye contact or smiling from a child with ASD then causes a parent to engage in fewer instances of these behaviors (Dawson et al., 1990; Williams, 2003). This causes a negative cycle of decreased social engagement, which impacts not only the parent-child relationship, but also later social skills of the child and the health and well-being of the parent as well (Gray, 2006). Parents of children with ASD also show increased levels of stress and lower quality of life (Tehee et al., 2009). These levels of stress have been shown to impact a parent's ability to recognize, accept, and act on their child's disorder (Tehee et al., 2009). The disrupted parent-child relationships in ASD can cause stress on the parent and decreased quality of life, which may then further impact the quality of the relationship and engagement between parent and child.

While parent-child relationships have been examined in ASD, it is not yet known if other disorders with social cognitive deficits also evidence altered parent-child interactions. For example, individuals with Prader-Willi Syndrome (PWS), a neurodevelopmental disorder caused by alterations to 15q11-q13, exhibit difficulties in social cognitive ability, with some increased risk in ASD as compared to the general population (Dimitropoulos & Schultz, 2007; Dykens et al., 2017). Specifically, children with PWS evidence similar difficulties with repetitive behaviors and insistence on sameness as children with ASD (Dykens et al., 2017). Additionally, even though recent findings suggest a lower instance of ASD in the PWS population (i.e. 12.3% versus previous findings of 25-41%), a high proportion of children still exhibit significant difficulties in social interactions (Dykens et al., 2017). Current findings in PWS also show increased stress and burden in caregivers who have children with this disorder, with parents reporting poorer quality of life, difficulties in family functioning, higher levels of depressions

and feelings of isolation, anger, and worry (Hodapp et al., 1997; Kayadjanian et al., 2018; Mazaheri et al., 2013).

Previous research also indicates children with PWS do evidence challenges in social cognitive functioning that may appear early in development (Dimitropoulos & Schultz, 2007; Dykens et al., 2017; Zyga et al., 2015). However, early parent-child interaction and how it relates to other factors such as parental stress has not been characterized in this population.

Understanding if parent-child engagement is disrupted in PWS at this early age may provide more insight on the deficits that may be evident in children with PWS and potential mechanisms of targeting these deficits through early intervention that engages both the parent and child. Given this, the current paper aims to provide a preliminary characterization of (1) parent-child interaction between parents of children with PWS as compared to TD parent-child dyads and (2) parental stress across parents of young children with PWS in comparison to parents of TD children. Further, in this paper we aim to then explore the relationship between parental stress and domains of parent-child interactions specifically within PWS. It is hypothesized that parents of children with PWS will show over involvement, provide too much unsolicited help to the child, and have a disrupted response to their child during a joint play task as compared to the TD parent-child dyads. Children with PWS are hypothesized to show less social interest and competence during a joint play task as compared to TD participants and the overall enjoyment of the dyad during the task is predicted to be lower in the PWS group. Parents with children who have PWS are predicted to exhibit greater stress in domains relating to their child, themselves as effective parents, and total life stress than parents of TD children.

## **Methods**

### **Participants**

Thirty-seven parent-child dyads (17 PWS; 20 TD), ages 3-5 years, participated in the current study. Child participants were included in the study if they were minimally verbal, able to sit at a table for short periods of time to complete tasks, and were not engaged in any clinical trials that aimed to alter mood, behavior, or social engagement. Further, participants with PWS were required to provide confirmation of their genetic diagnosis. Participants were excluded if the primary caregiver was not available for the parent-child interaction task. Participants with PWS were recruited nationally as part of a larger project through the Foundation for Prader-Willi Research (FPWR) and Prader-Willi Syndrome Association (PWSA) and TD participants were recruited locally through university and community online postings.

## Measures

**Parent-Child Interaction Task (Hudson & Rapee, 2001; NICHD):** Parent-child dyads were asked to play with a set of toys (i.e. blocks, small figurines, and cars) any way they liked for 5 minutes. This interaction was recorded and later coded based on a modified tangram task coding system (Hudson & Rapee, 2001) and Mother-Child Structured Interaction Rating Scales (adapted from NICHD Study of Early Child Care Research Network). Variables coded measured aspects of the parent's engagement (degree of parental involvement; unsolicited help; response to child), aspects of the child's ability to engage (social interest and social competence), and aspects of the dyads overall interaction (mutual enjoyment and engagement). Scales that measured degree of parental involvement, unsolicited help, response to child, and mutual enjoyment and engagement were taken from the modified tangram task coding system (Hudson & Rapee, 2001). Degree of parental involvement, unsolicited help, response to child were scored on an 8-point scale and mutual enjoyment and engagement was scored on a 5-point scale. For degree of parental involvement and unsolicited help, a score of 1 indicated no help or involvement where a

score of 8 indicated over involvement or unnecessary help. For response to child and mutual enjoyment and engagement, a score of 1 indicated a positive response or interaction whereas higher scores indicated a negative response or interaction. Scales that measured Social Interest and Social Competence were taken from the Mother-Child Structured Interaction Rating Scale (NICHD) and were coded on a 7-point scale, where a score of 1 indicated low interest or competence. These measures have been used as valid and reliable measures of the variables above across diverse child populations, including those with ASD (McDonald et al., 2016).

**Parenting Stress Inventory (PSI-4; Abidin, 2012).** A 120 item self-report questionnaire that assesses the magnitude of stress in the parent-child system. Items factor into 3 different domains of stress: child characteristics, parent characteristics, and situational/demographic characteristics. Child characteristics include: *Distractibility/Hyperactivity (DI)*, *Adaptability (AD)*, *Reinforces parent (RE;* i.e. assesses the parent's experience of interactions with his or her child as positively reinforcing), *Demandingness (DE)*, *Mood (MO)*, *Acceptability (AC;* i.e. assesses the extent to which child characteristics meet expectations of the parent). Parent characteristics include: *Competence (CO)*, *Isolation (IS)*, *Attachment (AT)*, *Health (HE)*, *Role Restriction (RO;* i.e. assesses the parent's sense of limited freedom and constrained personal identity as a result of the parenting role), *Depression (DP)*, *Spouse/Parenting Partner Relationship (SP)*. Levels of stress across domains are reported as T-scores, with average scores falling between 40-54. This measure has been used with parents of children with various developmental and psychological disorders, including ASD (Tomanik et al., 2004) and has been found to be a reliable and valid measure of stress across the domains described above.

## Results

### Demographics



Child participants in the two groups did not differ on age ( $M = 4.47$ ;  $SD = 0.92$ ). However, there was a significant difference in receptive language ability ( $F(1, 34) = 60.21$ ;  $p = 0.001$ ) as measured by the Peabody Picture Vocabulary Test (PPVT) and early cognitive ability ( $F(1, 34) = 14.72$ ;  $p = 0.001$ ) as measured by the visual reception subscale on the Mullen Scales of Early Learning, which is consistent with previous literature and ability in the PWS population (Roof et al., 2000). For parental characteristics, the majority were biological mothers (1 PWS biological father and 1 TD biological father participated). The two groups did not differ on mean age ( $M = 39.4$ ;  $SD = 5.25$ ), employment status (majority employed), and marital status (majority married). See Table 1 for full demographics.

### **Quality of Parent-Child Interactions**

Recorded parent-child interaction tasks were coded by the first author in compliance with the standardize scoring protocols. Coding reliability was conducted by a second coder also trained on the scoring protocols. Intraclass correlation coefficients (ICCs) for each variable were at or above 0.75, suggesting strong agreement between raters. Next, a series of one-way ANCOVAs was conducted, controlling for cognitive ability, to better understand how the PWS and TD groups differed on the quality of parent-child interaction as measured by the modified tangram coding system and the Mother-Child Structured Interaction Rating Scales. All variables significantly differed between the PWS and TD groups except for response to child. For parent's engagement, degree of parental involvement ( $F(1, 33) = 18.11$ ;  $p = 0.000$ ) and unsolicited help ( $F(1, 33) = 16.54$ ;  $p = 0.000$ ) were significantly higher in that PWS parents were over involved and more intrusive during the play task than the TD parents. For the child characteristics, children with PWS had significantly lower social interest ( $F(1, 33) = 12.68$ ;  $p = 0.001$ ) and competence ( $F(1, 33) = 20.09$ ;  $p = 0.000$ ) during the interaction than TD peers. Lastly, overall

mutual enjoyment and engagement was significantly lower in the PWS group ( $F(1, 33) = 11.25$ ;  $p = 0.002$ ). See Table 2 for full details.

### **Parenting Stress**

A series of one-way ANCOVAs, controlling for cognitive ability, was conducted to better understand how the PWS and TD groups differed in levels of parenting stress. Within the child domain, parents of children with PWS reported experiencing significantly more stress as it relates to their child as a whole ( $F(1, 33) = 5.18$ ;  $p = 0.02$ ) and also in domains relating to the child's distractibility/hyperactivity ( $F(1, 33) = 5.39$ ;  $p = 0.03$ ) and acceptability ( $F(1, 33) = 19.42$ ;  $p = 0.000$ ), while demandingness ( $F(1, 33) = 3.30$ ;  $p = 0.07$ ) trended towards significance as compared to parents of TD children. Within the parenting characteristics domain, stress was significantly higher in the PWS group in regards to parent role restriction ( $F(1, 33) = 7.386$ ;  $p = 0.01$ ) and trended towards significance in regards to health ( $F(1, 33) = 2.74$ ;  $p = 0.09$ ). There was no significant difference in overall parent or life stress between the PWS and TD groups. See Table 3 for full details.

### **Relationship Between Parenting Stress and Parent-Child Interactions in PWS**

Correlational analysis was conducted to better understand how parenting stress related to parent-child interaction in the PWS sample. Results indicated significant negative correlations between (1) a parent's response to their child and their view of competence as a parent ( $r(17) = -0.51$ ,  $p < 0.05$ ), (2) unsolicited help during the interaction task and parental feelings of competence ( $r(17) = -0.52$ ,  $p < 0.05$ ), isolation ( $r(17) = -0.54$ ,  $p < 0.05$ ) and health ( $r(17) = -0.48$ ;  $p < 0.05$ ), and (3) child's social competence during the interaction task and parental feelings of depression ( $r(17) = -0.52$ ;  $p > 0.05$ ) and spouse/parenting partner relationship ( $r(17) = -0.66$ ,  $p <$

0.05). These findings held at either significance or trending (unsolicited help x competence; response to child x competence) when language and IQ was controlled for.

### **Discussion**

The current study provides a preliminary characterization of (1) parent-child interaction, (2) parenting stress and (3) the relation of parent-child interaction with stress in a PWS sample of young children as compared to typical development. Results reported here suggest that early parent-child interactions are indeed disrupted in preschoolers with PWS and their primary caregiver as compared to TD parent-child dyads. Specifically, parents of children with PWS were significantly overinvolved and intrusive during interactions while children with PWS were significantly less socially interested or competent than their TD counterparts. Further, PWS dyads as a whole showed less shared enjoyment and engagement with one another during the interaction. However, PWS caregivers did not differ from TD parents in the response to their child. Specifically, as measured in the response to child scale, parents from both groups remained positive and encouraging during the interaction task. This finding is important and suggests that even though PWS parent-child dyads may show difficulty in other areas while interacting, parents are able to remain supportive, which can provide a strong foundation to build other skills on during these periods of engagement.

Parents of children with PWS reported increased levels of stress in various domains even at this early age, which is prior to significant syndrome specific food behaviors (Miller et al., 2011), in comparison to TD parents. Specifically, parents of children with PWS reported significantly more stress in domains relating to their child's behaviors, the demands these behaviors placed on the parent, and the fact that their child's behaviors did not meet the expectations of the parent. PWS parents also reported increased stress in the role restriction

domain, which may indicate a sense of limited freedom and constrained personal identity as a result of their parenting role. These results are commensurate with previous findings in the ASD literature which show that parents of children with ASD have substantially higher stress levels than parents of TD children (Bitsika & Sharpley, 2004). This elevated stress in ASD parents co-occurs with symptoms of depression and anxiety and has been associated with decreased quality of life and increased negative emotional and physical outcomes (Seymour et al., 2013). Relating these findings to the current study, the increased stress and burden (Kayadjanian et al., 2018) parents of children with PWS feel may suggest more global negative impacts on quality of life and mental and physical health in this caregiver population. This study also shows that this stress manifests before the typical onset of hyperphagia in this population, which suggests that other factors, perhaps relating to deficits in social development and disrupted parent-child engagement, may play into the stress and burden PWS caregivers experience. Future research is needed to better delineate the full impact of increased stress and burden in this population.

Parenting stress was also shown to be related to parent-child interaction. In the PWS dyads for example, child social competence negatively correlated with parental feelings of depression and the spouse/parenting partner relationship, indicating that parents with less socially competent children had higher levels of depression and stress surrounding their spousal/partner relationship. These findings held even when language and cognitive ability were controlled for, suggesting these results may be unique to the PWS population above and beyond what parents of children with intellectual or developmental delay may experience. Knowing this relationship exists between parental characteristics and child outcomes, a next step is understanding how to potentially positively impact both parent and child functioning. Indeed, a number of studies in ASD have shown that parenting stress can have a direct impact on

effectiveness of early behavioral therapies (Osbourne et al., 2008). Research has also found that early intervention that addressed not only the child's deficits but also parent factors through mindfulness-based techniques has led to reduced stress and depression in parents, increased mother-child interactions, and reduced behavioral problems in children with ASD (Neece, 2014; Singh et al., 2007). These findings highlight the need to intervene early in PWS and perhaps include a focus on both child *and* parent processes to increase the quality of parent-child interaction. This early intervention may then not only have positive effects in targeting socioemotional deficits in the child but also may improve parent mental health and partner relationships.

While this study has important implications for the PWS population, several limitations should be noted. First, the limited sample size did not allow for genetic subtype analysis within the PWS group. A focus of future work should be on better delineating if the parent-child relationship differs between subtypes expressed in PWS. A second limitation is the cross-sectional design utilized in this study which did not allow for longitudinal analysis or follow-up to understand the long-term impact of disrupted parent-child engagement on child functioning and parenting stress. A third limitation to note is that although the Parent-Child Interaction Task and rating systems administered in the current study have been previously used in populations with developmental disorders, such as ASD and ADHD, the task and coding has not been specifically validated on children with hypotonia. It is important to acknowledge the impact that hypotonia may have had on a child's ability to engage in the joint task, exhibit a wide range of facial expressions, imitate parent's behavior, etc. However, the visual reception subscale of the Mullen Scales of Early Learning was administered to child participants in the current study, which measures some areas of motor manipulation. All analyses controlled for performance on

the Mullen and significant differences were still found between the PWS and TD groups. Further, the measures used to score the parent-child task did not solely rely on the child's ability to engage and/or motor ability, but also the parent's approach to the task itself and their level of involvement. Moving forward, it will be important to examine the relationship between aspects of motor development and the quality of parent-child engagement within PWS in more detail given that hypotonia and other differences in motoric development occur at a high rate in this population.

Future work can continue to build off of the findings in this study, which are the first to show disrupted early PWS parent-child interaction. Previous factors have been shown to either predict or impact levels of stress parents with children with developmental disorders experience. For example, certain timeframes, such as time of diagnosis or transitional periods, may lead to increased stress and a need for more support (Tehee et al., 2009). Families with children with developmental disorders have also been found to show low levels of adaptability. This may then lead parents to use less effective coping strategies, which can further increase stress and decrease quality of life (Gray, 2006; Seymour et al., 2013). Projects designed to better understand if and how these various factors relate to either worse or better outcomes in caregivers and children with PWS could greatly inform behavioral intervention efforts, which may have a large impact in this population.

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Table 1: Demographics			
<i>Child Characteristics</i>			
	<b>PWS (n = 17)</b>	<b>TD (n = 20)</b>	<b>F-value/Chi-square Value</b>
<b>Age<sup>a</sup></b>	4.31 (1.02)	4.61 (0.83)	0.967
<b>Gender<sup>b</sup></b>	6 (35.3%)	7 (35.0%)	0.000
<b>PPVT</b>	87.69 (13.52)	120.1 (11.54)	60.21**
<b>Mullen (Visual Reception Scale)</b>	30.69 (9.17)	46.05 (13.74)	14.72**
<i>Parent Characteristics</i>			
<b>Age<sup>a</sup></b>	40.27 (6.11)	38.67 (4.46)	0.754
<b>Gender<sup>c</sup></b>	16 (94%)	19 (95%)	0.013
<b>Marital Status<sup>d</sup></b>	82.4%	75%	1.116
<b>Employment Status<sup>e</sup></b>	76.5%	90%	1.212

<sup>a</sup>age in years; <sup>b</sup>number female participants; <sup>c</sup>number biological mothers; <sup>d</sup>percent married; <sup>e</sup>percent employed; \*\*p < 0.01

Table 2: Parent-Child Interaction			
	<b>PWS (n = 17)</b>	<b>TD (n = 20)</b>	<b>F-value</b>
<i>Parent Variables</i>			
<b>Degree of Parental Involvement<sup>a</sup></b>	5.59 (1.33)	3.60 (0.94)	18.114**
<b>Unsolicited Help<sup>a</sup></b>	5.18 (1.51)	2.85 (1.27)	16.540**
<b>Response to Child</b>	2.88 (0.99)	2.50 (0.83)	1.492
<i>Child Variables</i>			
<b>Social Interest</b>	4.00 (1.17)	5.50 (0.51)	12.677**
<b>Social Competence</b>	4.71 (1.11)	6.60 (0.60)	20.085**
<i>Dyad Variables</i>			
<b>Mutual Enjoyment<sup>a</sup></b>	3.14 (0.66)	2.15 (0.81)	11.251**

<sup>a</sup>Higher scores indicate worse performance (i.e. overinvolvement, help that hinders the child's ability to engage, less cohesion and enjoyment); \*\*p < 0.01

Table 3: Parenting Stress Index			
	<b>PWS (n = 17)</b>	<b>TD (n = 20)</b>	<b>F-Value</b>
<i>Child Domain</i>			
<b>Distractibility/Hyperactivity (DI)</b>	51.82 (6.61)	43.35 (10.81)	5.397*
<b>Adaptability (AD)</b>	46.18 (8.59)	41.25 (10.17)	1.472
<b>Reinforces Parent (RE)</b>	45.59 (9.92)	40.50 (8.54)	0.996
<b>Demandingness (DE)</b>	55.12 (11.00)	44.75 (10.89)	3.296†
<b>Mood (MO)</b>	50.65 (9.84)	45.55 (11.34)	0.821
<b>Acceptability (AC)</b>	57.35 (7.53)	41.20 (8.78)	19.421**
<i>Parent Domain</i>			
<b>Competence (CO)</b>	44.18 (8.97)	43.65 (14.87)	0.006
<b>Isolation (IS)</b>	49.47 (9.33)	46.60 (12.57)	0.507
<b>Attachment (AT)</b>	44.82 (5.69)	42.50 (9.21)	0.475
<b>Health (HE)</b>	49.29 (11.97)	42.65 (10.90)	2.743†
<b>Role Restriction (RO)</b>	51.06 (7.54)	42.65 (10.28)	7.386**
<b>Depression (DP)</b>	48.24 (8.66)	46.90 (13.87)	0.151
<b>Spouse/Parenting Partner Relationship (SP)</b>	47.18 (9.52)	49.65 (15.19)	0.362
<i>Overall Stress Scores</i>			
<b>Child Domain Stress</b>	51.47 (7.79)	41.75 (9.59)	5.176*
<b>Parent Domain Stress</b>	46.65 (7.02)	44.50 (11.92)	0.362
<b>Life Stress</b>	46.59 (9.35)	43.20 (10.94)	1.797
<b>Total Stress</b>	48.76 (7.20)	43.00 (10.59)	2.583

†p < 0.10; \*p < 0.05; \*\*p < 0.01; Means(SD) reported as T-scores