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# What worries parents of a child with Autism? Evidence from a biomarker for chronic stress

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### ABSTRACT

**Background:** Previous studies have reported correlations between various aspects of the behaviour and symptomatology of children with Autism Spectrum Disorder (ASD) and their parents' self-reports of stress via standardised scales.

**Aims:** To extend that literature, a physiological index of parental chronic stress was used instead of their self-reports—dysregulation of the Diurnal Rhythm (DR) of the Hypothalamic-Pituitary-Adrenal (HPA) axis.

**Methods:** A sample of 149 parents of a child with ASD provided salivary cortisol at the predicted time of daily maximum cortisol concentration and at a time of daily lower concentration. Adherence to the predicted DR was assessed via a dichotomous (present/not-present) as well as a continuous measure, and MANOVA and linear regression were used to detect significant associations between ASD-related variables in their children and parents' DR.

**Results:** Identified only a single significant correlate of DR dysregulation in both statistical procedures—Self-Injurious Behaviour (SIB) exhibited by their child and observed by the parents.

**Conclusions and Implications:** These findings extend previous data using self-report indices of parental stress and should be included in parent-support settings to alert parents to the long-term health effects of the stress they experience in regard to their child's SIB.

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### What this paper adds.

Stress in parents of a child with ASD has been previously measured by paper-and-pencil or interview scales. While valuable, data from such scales may be open to unwitting bias. One method of overcoming that possible self-report bias is to use a biological marker of chronic stress. In this study, the dysregulation of the HPA axis Diurnal Rhythm (DR) was used as such a biomarker, and results provided an extension of previous findings based upon self-report alone. The long-term adverse health consequences of DR dysregulation add to the relevance of these findings for supporting parents of children with ASD.

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## 1. Introduction

### 1.1. Parenting stress in ASD

Parenting a child with Autism Spectrum Disorders (ASD) has been shown to be a stressful experience (Bouma & Schweitzer, 1990; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Sharpley, Bitsika, & Efremidis, 1997), often elevating parental anxiety and/or depression above levels reported by parents of non-ASD children (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Weiss, 2002). In a meta-analysis of 26 studies, Hayes and Watson (2013) also found that, as well as experiencing higher levels of parenting stress than parents of typical children, parents of ASD children also reported stress levels that were significantly higher than parents of children with other non-ASD disabilities. Those authors commented that the evidence regarding elevated stress among parents of children with ASD was conclusive and that future investigations should focus upon the factors that contribute to, and moderate, that stress.

## 2. Sources of parental stress

Several studies have attempted to identify the ASD child-based factors that are most likely to contribute to parental stress, and these have included severity of ASD symptoms, level of functioning, child's age, and adaptive behaviour (Davis & Carter, 2008; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). There is also some evidence that the children's externalising (e.g., aggression, tantrums, self-injurious behaviour) and internalising (withdrawal, anxiety, fear) behaviours had significant relationships with parental stress over time (Zaidman-Zait et al., 2014). In their study of a range of behaviour problems and parental stress, Lecavalier, Leone and Wiltz (2006) noted that conduct problems such as being defiant, disobedient and physically attacking people were most strongly associated with parent and teacher stress. These may be loosely grouped under the title 'oppositional and aggressive behaviour', and several recent empirical studies and reviews have specifically focused upon the prevalence of oppositional behaviour in children with ASD. For example, Mayes et al. (2012) reported more than 40% of children with ASD also met the diagnostic criteria for Oppositional-Defiant Disorder (APA, 2013), well above the reported prevalence of 3.3% for the general community (APA, 2013), which was confirmed by Kaat and Lecavalier's (2013) review of 55 studies of this issue. In terms of aggression, Kanne and Mazurek (2011) found that 68% of a sample of 633 children with ASD demonstrated aggression but that this prevalence of aggression was not able to be predicted by severity of ASD symptoms or IQ.

### 2.1. Types of child aggression

Aggression may be directed at others or at oneself, the latter being defined as self-injurious behaviour (SIB). SIB is considerably more prevalent among children with ASD than their non-ASD peers (Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007), with a reported rate of 50% of children with ASD exhibiting SIB in one sample of 222 children (Baghdadli, Pascal, Grisi, & Aussilloux, 2003). The presence of intellectual disabilities may confound the prevalence rates of SIB in children with ASD (Matson & LoVullo, 2008) but this is yet to be definitively determined. Although it would be reasonable that SIB might be a particularly stressful aspect of aggression for parents of children with ASD (or any parents), that relationship has not yet been reported in the literature. Examination of the relative contribution that aggression to self (or SIB) versus aggression to others might have upon parental stress could provide valuable information for the targeting of parent-support training.

### 2.2. Measurement of parental stress

Most of the studies of parental stress mentioned above have used the Parenting Stress Index (PSI) or its Short Form as a self-report scale completed by the parents themselves to measure their parenting stress. The PSI has adequate validity and reliability and is comprised of three subscales (Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child Characteristics). The first of these subscales uses items such as "Since having a child I feel that I am almost never able to do the things I like to do"; Dysfunctional Interaction is measured by items relating to whether the parent feels that their child likes them; and the child's Difficult Characteristics items are focused on the problematic behaviour of the child. Although the PSI is clearly valuable when measuring these three subsets of overall self-reported stress, it is open to the potential confound of parent bias in reporting. That is, some parents may feel uncomfortable in making negative statements about their child's behaviour, or the effect which their child has had upon their lives, and may then bias their responses away from the negative so that they under-report their level of stress. Further, although the PSI is well-validated and psychometrically sound, it does not provide any direct information regarding the physiological state of parents that might be obtained via biological indicators of stress. That is, although self-report data reflect how respondents perceive themselves and how they perceive their psychological stress state, biological markers can provide an objective measure of the physiological state of those parents that can elaborate upon their self-perceptions, thus reducing the possibly biasing effects of self-reports. This is particularly valuable when participants may be unaware of their physiological state and the effects of stress upon it.

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