With a Little Help from my Friends: Psychological, Endocrine and Health Corollaries of Social Support in Parental Caregivers of Children with Autism or ADHD

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Abstract

Elevated psychological distress and concomitant dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis has been implicated as one pathway that links the stress of caregiving with adverse health outcomes. This study assessed whether perceived social support might mitigate the psychological, endocrine and health consequences of caregiver stress in parents of children with autism and attention deficit hyperactivity disorder (ADHD). Parental caregivers completed measures of psychological distress, perceived availability of social support and physical health complaints. To capture important parameters of the basal diurnal cortisol pattern, caregivers collected salivary cortisol at waking, 30 minutes post waking, 1200h and 2200h on two consecutive weekdays. Psychological distress and self reported physical health complaints were inversely related to scores on all support subscales: tangible, belonging, self esteem and appraisal. Results further revealed a significant, positive association between magnitude of the cortisol awakening response (CAR) and caregivers' self esteem. As a buffer between the stress of caregiving and adverse physical health outcomes, social support acts to reduce stress appraisals and mitigate disturbances of the HPA axis. Moving forward, intervention programmes might seek to increase caregivers' perceived availability of social resources.

Key words: ADHD; autism; caregiver; cortisol; physical health complaints; social support; stress appraisals.

Introduction

As a prototypical model for chronic stress, informal caregivers of medically fragile children demonstrate elevated psychological distress (Lovell & Wetherell, 2011; Miller et al., 2008; Rohleder, Marin, Ma, & Miller, 2009; Weiss, 2002), disrupted patterns of cortisol secretion (Miller, Cohen, & Ritchey, 2002; Seltzer et al., 2009) and report more frequent complaints of physical ill health (Bella, Garcia, & Spadari-Bratfisch, 2011; Byrne, Hurley, Daly, & Cunningham, 2010; Lovell, Moss, & Wetherell, in press; Moskowitz & Epel, 2006). As the final effector hormone of the HPA axis, cortisol displays a robust basal diurnal pattern; concentrations increase within 30-45 minutes post waking (cortisol awakening response, [CAR]), steadily decline across the day (diurnal cortisol slope) and reach a trough at around midnight (Smyth et al., 1997). By boosting levels of cortisol, the post waking response has been regarded as an adaptive mechanism that equips the host with the physiological resources needed to meet anticipated demands (Fries, Dettenborn, & Kirschbaum, 2009). In support, research has revealed a markedly steeper CAR on weekdays (i.e., workdays) compared with more leisurely weekend days (Kunz-Ebrecht, Kirschbaum, & Steptoe, 2004; Schlotz, Hellhammer, Schulz, & Stone, 2004). A steeper morning response has also been observed among individuals experiencing work overload (Steptoe, 2000) and on the morning of a real life, social evaluative performance stressor (Rohleder, Beulen, Chen, Wolf, & Kirschbaum, 2007). Research, however, has demonstrated a blunted CAR in caregivers of children experiencing cerebral palsy (Bella et al., 2011) and autistic spectrum conditions (Seltzer et al., 2010). Reduced bioavailability of cortisol

has been implicated as one physiological pathway that underlies the effects of chronic stress on a broad catalogue of clinical outcomes including, burnout (Heim, Ehlert, & Hellhammer, 2000), chronic fatigue syndrome (Van Houdenhove, Van Den Eede, & Luyten, 2009) and fibromyalgia (Gunnar & Vasquez, 2000).

Social support, the availability of family and friends that can provide psychological and material resources (Cohen & Ashby Wills, 1985) mitigates psychological distress (Bozo et al., 2010; Weiss et al., 2002) and buffers against dysregulation of the HPA axis (Miller et al., 2002) and physical and mental health complaints (Lin et al., 2009; Sawyer et al., 2010) in caregivers of medically fragile children. The stress buffering hypothesis states that, as a function of greater coping resources, stress appraisals are reduced in supported individuals (Cohen & Ashby Wills, 1985). Reduced stress appraisals have been implicated as one pathway that underlies support related disparities in HPA activity, both in chronically stressed populations (Turner Cobb, Sephton, Koopman, Blake-Mortimer, & Spiegel, 2000) and in response to acutely stressful tasks in the lab (Kirschbaum, Klauer, Filipp, & Hellhammer, 1995). Researchers have demonstrated how, as a dyadic interaction, the psychophysiological well being of the caregiver is indelibly linked with the quality of life of the care recipient (Burgess & Gutstein, 2007); therefore, by identifying pathways that help offset the psychophysiological consequences of caregiver stress, researchers might be better poised to improve quality of life for the care recipient.

We assessed the psychological, endocrine and health corollaries of social support in parental caregivers of children with autism or ADHD. On the basis of past work with similar cohorts, we predicted that greater perceived availability of social resources would be related to (a) diminished psychological distress, (b) more adaptive HPA function and (c) fewer complaints of physical ill health.

Methods

Participants

All procedures received ethical approval by the School of Life Sciences ethics committee. Parents were recruited according to the following criteria: (a) providing care for at least one child with autism or ADHD, and (b) living at home on a full time basis, (c) not pregnant, breast feeding, taking steroidal, or hormone replacement medication, and (d) not managing chronic illness. Parents that satisfied these criteria were invited to provide informed consent. Parents were recruited from local and regional support groups, schools and charities, and were reimbursed £10.00 for their time. Of 56 parents recruited, two withdrew citing time constraints. An additional seven failed to return any saliva samples or provide sufficient saliva for biochemical assay. Non adherence with the saliva sampling protocol can invalidate the reliability of diurnal cortisol measurement (Kudielka, Broderick, & Kirschbaum, 2003); therefore, salivary cortisol data was excluded for two parents that reported protocol non adherence. Analyses were conducted on a final sample composed of 45 caregivers. Table 1 presents characteristics of the sample.

INSERT TABLE 1 HERE

Procedures

Parents were asked to complete questionnaires and provided materials to perform ambulatory collection of salivary cortisol. Diurnal cortisol measurement can, on any one day, be influenced to a large extent by state level variables such as, time of waking, quality and duration of sleep (Griefahn & Robens, 2008; Hellhammer et al., 2007; Stalder, Hucklebridge, Evans, & Clow, 2009). To reliably assess the diurnal

cortisol pattern, therefore, researchers have recommended that participants collect between four and six saliva samples on two consecutive weekdays (Hellhammer et al., 2007). Parents were instructed to collect salivary cortisol at waking, 30 minutes post waking, 1200h and 2200h on two consecutive weekdays. Cortisol was sampled using the Salivette, Sarstedt Ltd. This requires participants to chew a sterile cotton swab for 1-2 minutes and deposit swabs into plastic collection tubes, once saturated. To assist with adherence to the protocol, all parents were provided detailed written instructions that emphasised the importance of exact time of sampling. Researchers have demonstrated that self reported adherence has been shown to be equally as reliable as more objective, electronic measures of adherence with the saliva sampling protocol (Okun et al., 2010; Seltzer et al., 2010); therefore, parents were provided a paper diary and instructed to record waking and sampling times as accurately as possible on all sampling days. Parents were also asked to record information pertaining to stage of the menstrual cycle, use of oral contraceptives and, for 45 minutes prior to sample collection, abstain from behaviours known to affect the measurement of cortisol in saliva: (a) consumption of food, caffeinated / alcoholic beverages, (b) exercise (c) nicotine and (d) brushing teeth and use of mouthwash (Kudielka, Hellhammer, & Wust, 2009). Parents were instructed to store collected samples in a domestic freezer until returned to the research team. Returned samples were stored frozen at -20°C. Assays were performed in house using the luminescence immunoassay method (IBL Hamburg, Germany). The mean intra-assay coefficient was 7.1% and mean inter-assay coefficient was 10.7% respectively.

Psychosocial Assessment

Psychological distress was quantified using the 10 item *Perceived Stress Scale* (PSS) (Cohen, Kamarck, & Mermelstein, 1983). The PSS, though not a diagnostic

instrument, measures the extent to which participants perceive their lives to be overwhelming, uncontrollable and unpredictable. Scale responses range from 0 (*never*) to 4 (*very often*) and items are summed to yield a total score. Higher scores indicate greater perceived levels of stress, experienced over the previous month. The PSS achieved excellent psychometrics in our sample (α = .87). Depression and anxiety were assessed using the 14 item *Hospital Anxiety and Depression Scale* (HADS) (Zigmond & Snaith, 1983). Scale responses range from 0 (*never*) to 3 (*considerable*) and are summed to produce separate scores for anxiety and depression. Higher scores indicate more frequent feelings of anxiety and depressive symptoms. Scores between 0-7 are considered normal. Scores between 8- 10 are indicative of borderline mood disorder and scores > 11 indicates probable mood disorder (Snaith, 2003). The HADS achieved excellent psychometrics in our sample (α = 0.91). Frequencies of 54 common, physical health complaints were quantified using the *Pennebaker Inventory of Limbic Languidness* (PILL) (Pennebaker, 1982). Scale responses range from 1 (*never / almost never*) to 5 (*more than once per week*). Items experienced by the respondent more than once per month are summed to formulate an index of total complaint frequency. Internal consistency in the sample was high (α = .96). Perceived availability of social resources was assessed using the *Interpersonal Support Evaluation Checklist* (ISEL) (Cohen & Hoberman, 1983). The scale comprises 40 statements that measure participants' perceived availability of social resources across four subscales: appraisal (availability of confidants to discuss one's problems), belonging (availability to interact with others), tangible (availability of material aid) and self esteem (availability of a favourable comparison, when comparing oneself with others). Higher scores indicate greater perceived availability and quality of social resources. Internal consistency in the sample was high (α = .94).

Physiological Assessment

To normalize distributions, raw cortisol values were $\log_{10}$ transformed and data for each sampling day used to estimate parameters of the diurnal cortisol pattern. The CAR was calculated as the difference between cortisol at waking and 30 minutes post waking. Mean cortisol output across the day was estimated by summing all four cortisol values. To assess the diurnal cortisol slope, a regression line was fitted separately for each participant that predicted cortisol values from time since waking. Steeper slopes indicate greater rate of diurnal change and are represented by smaller β values (larger negative values). Higher β values (as they approach / cross zero) indicate flatter cortisol slopes and dysregulation of the HPA axis (Smyth et al., 1997). In keeping with most recent work, cortisol values were averaged across sampling days to obtain more reliable indices of HPA activity (Rohleder et al., 2009; Turner Cobb et al., 2010).

Results

Potential Confounds

Variables that might provide alternative explanations for associations between social support and psychophysiological outcomes were assessed. These included: gender, age, weight, height, body mass index, nicotine and alcohol consumption, frequency of exercise, use of antidepressants, number of children and annual household income. Independent *t* tests revealed that, compared with fathers, levels of anxiety were significantly higher in mothers (t (43) = 2.41, p = .02). A notable trend for an elevated CAR in mothers was also observed (t (43) = 1.94, p = .06). Bivariate correlations revealed a significant, positive relationship between the diurnal cortisol slope and both nicotine consumption (r = 0.50, p < .01) and number of children in the household (r = 0.41, p < .01). A notable trend for flatter cortisol slopes in younger caregivers was also

observed (r = -0.26, p = .08). Results revealed a significant, positive association between magnitude of the CAR and nicotine consumption (r = 0.35, p = .02). Mean diurnal cortisol output was positively related to both caregiver height (r = 0.30, p = .05) and number of children in the household (r = 0.30, p = .05). Subsequent analyses adjusted for these variables. Table 2 presents means and standard deviations for psychophysiological measures in the sample.

INSERT TABLE 2 HERE

Psychological Measures and Social Support

Bivariate correlations revealed a significant, inverse relationship between depression and scores on all subscales of the ISEL (all ps < .03). Perceived levels of stress were inversely related to caregivers' perceived availability of appraisal support (r = -0.40, p < .01) and self esteem (r = -0.53, p < .01). Controlling for gender, partial correlations yielded a significant inverse relationship between anxiety and the appraisal (r = -0.46, p < .01), belonging (r = -0.40, p < .01) and self esteem (r = -0.56, p < .01) subscales of the ISEL. Results further revealed a significant inverse correlation between self reported physical health complaints and scores on all subscales of the ISEL (all ps < 0.02). Table 3 presents correlation coefficients between social support scores and measures of psychological distress, cortisol parameters and physical health complaints.

INSERT TABLE 3 HERE

Physiological Measures and Social Support

Controlling for gender and nicotine consumption, the morning cortisol response was significantly greater in caregivers that reported greater levels of self esteem (r = 0.35, p = .02). Controlling for age, nicotine consumption and number of children in the household, relationships between other diurnal parameters and support scores failed to reach statistical significance (all *ps* > .40).

Discussion

Measures of psychological distress, anxiety and depression indicate that caregivers scored in the range of borderline mood disorder (Snaith, 2003) and, therefore, are at markedly greater risk for psychological morbidity. These data emphasise the importance of identifying buffers that can alleviate psychological distress in caregiver populations. Those caregivers that reported greater perceived availability of social resources demonstrated diminished levels of psychological distress, steeper morning cortisol response and reported fewer complaints of physical ill health. In support of the stress buffering hypothesis, caregivers that reported greater social resources appraised their role of caregiver to be less stressful, thereby, buffering against maladaptive physiological processes (i.e., attenuation of the CAR) and concomitant decrements in physical health status. Reduced stress appraisals have been identified as one pathway that underlies support related disparities in HPA activity in other chronically stressed populations (Turner Cobb et al., 2000) and in response to acutely stressful tasks in the lab (Kirschbaum et al., 1995). Research has implicated reduced bioavailability of cortisol in the aetiologies of stress related bodily disorders including, burnout (Heim et al., 2000), chronic fatigue syndrome (Van Houdenhove et al., 2009) and fibromyalgia (Gunnar & Vasquez, 2000). These data highlight the potential clinical

relevance of a blunted CAR in caregivers that scored lower on the self esteem subscale of the ISEL.

The current work should be evaluated in the context of its limitations. Though steps were taken to ensure reliable cortisol measurement (Hellhammer et al., 2007), sampling across a more protracted period (e.g., waking, 15, 30, 45 and 60 minutes post waking) would have provided a more robust measure of the morning cortisol response (Stalder et al., 2009). The cross sectional nature of the study precludes drawing inferences about the direction of observed relationships between study variables. Longitudinal research, using larger samples is needed to clarify the direction and sequential relationships between social support and cortisol patterns in this population.

In conclusion, as a buffer between the stress of caregiving and adverse physical health outcomes, social support acts to reduce stress appraisals and mitigate dysregulation of the HPA axis. These findings are important, as they are the first to demonstrate how social support might mitigate psychophysiological disturbances and offset adverse physical health outcomes in parents of medically fragile children. Moving forward, intervention programmes might seek to increase caregivers' perceived availability of social resources.

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Table 1

Characteristics of the Sample (n = 45)

Caregivers	
Children with autism	33 (73%)
Children with ADHD	12 (27%)
Gender	
Mothers	39 (87%)
Fathers	6 (13%)
Age, years (mean ± SD**)**	44.8 (7.3)
Height, inches (mean ± SD)	65.1 (2.9)
Weight, lbs (mean ± SD)	165 (41.2)
Body mass index (mean ± SD)	27.3 (6.1)
Annual household income (mean ± SD)	£36,076 (£27,851)
Exercise, days per week (mean ± SD)	3.0 (2.4)
Number of children in the household	
1 child	10 (22%)
2-3 children	29 (64%)
> 3 children	6 (14%)
Marital status	
Partnered	35 (78%)
Not partnered	10 (22%)
Nicotine consumption	
Smoker	6 (13%)
Non smoker	39 (87%)
Alcohol consumption (units per week)	
< 5 units	28 (62%)
5-10 units	12 (27%)
>10 units	5 (11%)
Use of antidepressants medications	
Yes	14 (33%)
No	31 (67%)

Table 2

Means and Standard Deviations for Psychological Distress, Cortisol Parameters and Physical Health Complaints in the Sample

Support Subscales *(mean ± SD)*	
Appraisal	21.7 (6.5)
Belonging	20.0 (6.3)
Tangible	21.6 (6.5)
Self esteem	17.4 (4.7)
Psychological Measures *(mean ± SD)*	
Perceived stress	22.4 (6.5)
Anxiety	9.8 (4.4)
Depression	8.9 (4.4)
Physical Health Complaints *(mean ± SD)*	17.6 (11.5)
Cortisol Parameters *(mean ± SD)*	
Waking (nmol/L)	14.9 (6.3)
30 minutes post waking (nmol/L)	20.1 (8.3)
1200h (n/mol/L)	6.9 (5.5)
2200h (n/mol/L)	3.2 (5.6)
CAR (nmol/L)	5.3 (8.4)
Cortisol slope (β)	-0.82 (0.3)
Mean cortisol output (nmol/L)	11.3 (4.8)

Table 3

Correlation Coefficients for Social Support Scores and Psychophysiological Measures

	SUPPORT SUBSCALES			
	Appraisal	Belonging	Tangible	Self Esteem
Psychological Measures				
Perceived stress	-0.40**	-0.25	-0.23	-0.53**
Anxiety	-0.46**	-0.40**	-0.29	-0.56**
Depression	-0.48**	-0.49**	-0.33*	-0.54**
Physical Health Complaints	-0.54**	-0.49**	-0.53**	-0.36*
Cortisol Parameters				
Cortisol awakening response	0.17	0.20	0.11	0.35*
Diurnal cortisol slope	0.05	0.00	0.08	0.13
Mean output of cortisol	0.05	0.01	0.10	-0.12

*$p = < 0.05$
**$p = < 0.01$