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Relationship between self-reported health and stress in mothers of children with
Autism Spectrum Disorders

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Abstract

The current study explores the relationship between various forms of experienced stress (general stress and parenting stress) and both health-related quality of life (QoL) and reported physical health symptoms. One hundred and twenty-two mothers of children with Autism Spectrum Disorder responded to an online survey that included questionnaires on general stress, parenting stress, health-related QoL, and physical symptoms. The results suggested that perceived general stress was associated with both a reduced health-related QoL and more physical symptoms. However, parenting stress was only associated with a reduced health-related QoL, and not with physical health. These results are discussed in relation to the complex impact of prolonged and predictable parenting stress on the cortisol response and immune system.

Key words: physical health, health-related quality of life, parenting stress, life stress, immune function, ASD.

Parents of children with Autism Spectrum Disorder (ASD) are known to report higher levels of parenting stress than almost any other group of parents of children with disabilities (Blacher and McIntyre 2006; Eisenhower, Baker, and Blacher, 2005; Osborne and Reed, 2009a). High levels of parenting stress have been implicated as bi-directionally related to levels of child behaviour problems (Lecavalier, Leone, and Wiltz, 2007; Osborne and Reed, 2009b), and also to reduced efficacy of treatments for the children (Osborne, McHugh, Saunders, and Reed, 2008). In addition, parents of children with ASD often report high levels of tiredness and fatigue (Emerson, 2003; Hedov, Anneren, and Wikblad, 2000), and a range of mental health problems (Boyd, 2002; Wolf, Noh, Fisman, and Speechley, 1989). It has also been noted that mothers of children with ASD report worse health-related QoL than mothers of typically developing children (Allik et al., 2006; Hedov et al., 2000; Mungo et al., 2007). For example, Allik et al. (2006) conducted a survey in which mothers rated their health-related QoL as worse than mothers of other groups of disabled children and mothers of typically developing children (see also Hedov et al., 2000). The current study assessed the degree to which there was a relationship between parenting stress, assessed in a variety of ways, and levels of health-related quality of life and of ill health reported by parents.

There is a difference between health-related QoL, which assesses the degree to which daily living is impacted by health issues, and the person's actual health status – that is, the numbers of symptoms that they actually report (see Osborne, Bindemann, Noble, and Reed, 2014, for a discussion). In fact, there have been few, if any, direct assessments of the physical health problems experienced by the parent. There are indications that physiological indices of poor health are associated with being a parent of a child with a long-term or developmental disorder (see Epel et al., 2004; Gallagher, Phillipis, Drayson, and Carroll, 2009; Seltzer et al., 2010). For example, parents of children with long-term conditions have faster reduction in telomeres, which are the parts of chromosomes that protect against cellular

damage (Epel et al., 2004), and they also have a poor antibody response to some vaccinations (Gallagher et al. 2009). Moreover, parents of individuals with ASD demonstrate a different pattern of cortisol level throughout the day compared to mothers of typically-developing individuals (Seltzer et al., 2010). This disrupted pattern of cortisol activity in parents of children with ASD seems to be related to the behaviour problems exhibited by their child, the mental health problems of the parents, and parental employment status (Dykens and Lambert, 2013), as well as being mediated by levels of social support (Lovell, Moss, and Wetherell, 2012).

The above findings suggest that parents of children with ASD experience a range of psychological and physiological disruptions. However, there remains a lack of direct evidence that parents of children with ASD actually report experiencing poor health, as opposed to displaying disrupted physiological signs (Dykens and Lampert, 2013; Gallagher et al., 2009; Seltzer et al., 2010), and worse health-related QoL (Allik et al., 2006; Mungo et al., 2007), which are not always a perfect indicator of poor health. The degree to which such ill health is reported by parents of children with ASD, and its relationship with a range of potential predictive factors, will be explored in the current study.

The precise aspects of physical health that may be impacted by parenting a child with ASD are not clear a priori, but a number of considerations can be taken into account in narrowing the field of study. It is known that mental health problems (Dickerson and Kemeny, 2004; Irwin, Patterson, Smith, Caldwell, Brown, Gillin, and Grant, 1990; Kim, Park, Leem, Jung, and Hwang, 2011) and disrupted cortisol levels (McClelland, Floor, Davidson, and Saron, 1980) lead to decreased immune function. This suggests that being a parent with ASD might impact heavily on immune function, which would imply that illnesses such as the common cold (Heikkinen and Järvinen, 2003), influenza (WHO, 2013), cold sores (Grout and Barber, 1976), pneumonia (Glaser, Sheridan, Malarkey, MacCallum, and Kiecolt-

Glaser, 2000), sepsis (Hass and Schauenstein, 2001), and skin infections (Aberg et al., 2007), may be best to focus upon when assessing the impact of parenting an ASD child on physical health. In determining the degree to which these ailments may be experienced, previous work has examined self-reports of the symptoms typically correlated with poor immune function (Adam, Meinlschmidt, and Lieb, 2013; Kim, Baik, Park, Kim, Choi, and Kim, 2011; Reed, Vile, Osborne, Romano, and Truzoli, 2015). Self-report is regarded as a strong method in this context, as such symptoms are easy to self-discriminate, are often not reported to health professionals (and so do not show up on medical records), and are often experienced without any objectively verifiable viral cause (Heikkinen and Järvinen, 2003). Given this, an assessment of the levels of immune-related problems will be made, alongside an assessment of the health-related QoL (i.e. the impact of these symptoms) – which may well differ from the direct assessment of symptom number.

The factors that predict poor physical health or health-related QoL in parents of children with ASD are not entirely apparent from the existing literature, and there are a range of potential factors that might play a role. In particular, it has been suggested that levels of stress are important for both immune function (McClelland et al., 1980) and health-related QoL (Allik et al., 2006). However, stressors can come from a variety of sources for parents of children with ASD: it can be related directly to parenting a child with ASD (parenting stress), or form the range of additional life stressors that such parents may experience (see Osborne and Reed, 2009b, for a discussion). It is certainly the case that issues such as employment (Hill, Jones, Lang, Yarker, and Patterson, 2014; Montes and Halterman, 2008), financial issues (Knapp, Romeo, and Beecham, 2009), and relationships and divorce (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, and Bolt, 2010) are important potentially disruptive factors in lives of parents of individuals with ASD, and each of these can impact on health and its physiological correlates (see Barrington, Stafford, Hamer, Beresford,

Koepsell, and Steptoe, 2014; Marmot and Bell, 2012; Repetti, Matthews, and Waldron, 1989). Given that it is currently unclear whether parenting stress or general life stressors associated with being a parent of a child with ASD are more directly related to health issues for this group of parents, the current report sought to establish the relationship between levels of both general stress, and stress particular to parenting, with the health-related QoL and health status for this group.

In summary, the current report measured levels of general stress and levels of parenting stress in mothers of children with ASD, and related these two types stress to levels of self-reported immune function (assessed by the numbers of symptoms experienced) and also to health-related QoL. It is not clear a priori which of these two types of stress would impact on actual physical symptoms or on the related QoL in this group of mothers, and this was the main focus of the current work in addition to gathering direct information about whether physical symptoms, as well as the physiological correlates of ill health previously studied, would be related to such forms of stress.

Method

Participants

The survey was sent to 97 parent support groups found online, and they were asked to post a link to the study on their websites (see Procedure section below). No exclusion criteria were placed on the participants in terms of their age or that of their children, as it was not known if any of these variables would impact on the outcome, and it was felt that a wider rather than smaller range of participants might highlight any important relationships between these variables are health functioning. One hundred and twenty-two mothers of children diagnosed with an ASD responded to this questionnaire; with a range of 0 to 8 mothers

responding from each support group. Unfortunately, it is impossible to calculate how many mothers saw the survey and did not respond.

The mean age of the mothers was 41.49 (\pm 7.79; range = 20 – 64) years. Of these participants, 44 (36.1%) were single, and 78 (63.1%) were in a relationship; 48 (39.3%) were not in paid work, and 74 (60.7%) were employed. In terms of their children, there were 97 (79.5%) males and 25 (20.5%) females, their mean age was 11.48 (\pm 6.20; range = 2 – 44) years, and their mean age at diagnosis was 5.84 (\pm 3.20; range = 2 – 38) years. The diagnoses reported for the children by their mothers (in response to the question: “What is the official diagnosis given to your child by the medical professional? Please specify any other diagnoses that have been given to your child.”) were: 69 (56.6%) autism, 39 (32%) Asperger, and 14 (10.7%) autism with an additional co-morbidity. The mothers were also asked about how many other children they had: 68 (55.7%) responded 0; 37 (30.3%) responded 1; 15 (12.3%) responded 2; and 2 (1.6%) responded 3. Mothers were also asked if they had other children with a disability than the child they were responding about in this survey, 19 (15.5%) responded that they had – which represents 35.2% of those with more than 1 child.

Questionnaires

Perceived Stress Questionnaire (PSQ; Levenstein, Prantera, Varvo, Scribano, Berto, Luzi, and Andreoli, 1993) is a widely-used measure of general life stress. The measure consists of 30 items scored on a 4-point Likert-type scale (*Almost Never, Sometimes, Often, Usually*). Example questions are: “*You have too many things to do.*” and “*Your problems seem to be piling up.*”. The reliability (Chronbach alpha) of the scale is .90 (Levenstein et al., 1993).

Questionnaire on Resources and Stress (QRS; Friedrich, Greenberg, and Crnic, 1983) measures stress related to parenting a child with a developmental disability. It is a 52-item,

self-administered, true or false, tool, designed to measure parental perceptions of the impact of a developmentally delayed, or chronically ill, child on other family members. Example items are: “*Sometimes I avoid taking [my child] out in public.*” and “*It is easy to communicate with [my child].*”. The reliability (Cronbach alpha) of the scale is .89 (Friedrich et al., 1993).

General Health Questionnaire (GHQ-28; Goldberg and Hillier, 1979) measures health-related QoL across a range of psychiatric and health problems. It has 28 items requiring a response on a 4-point Likert-type scale (*Not at all, No more than usual, Rather more than usual, Much more than usual*). Example questions ask whether you have recently: “*being getting a feeling of tightness or pressure in your head*” and “*felt life was entirely hopeless.*” The internal reliability of total score is .92 (Goldberg and Hillier, 1979).

Immune Function Questionnaire (IFQ; Reed et al., 2015) assess the frequency of various symptoms associated with poor immune function. Based on their frequency in the general population, and direct relation to immune deficiencies, the following conditions were selected as a base for the items on the questionnaire: common cold (Heikkinen and Järvinen, 2003), influenza (WHO, 2013), cold sores (Grout and Barber, 1976), pneumonia (Glaser et al., 2000), sepsis (Hass and Schauenstein, 2001), long healing injuries (Cohen, Janciki-Deverts, and Miller, 2007), and skin infections (Aberg et al., 2007). Following the analysis of the major symptoms of these conditions, 19 symptom items were included on the questionnaire as signs of weakened immune system functioning: sore throat, headaches, flu, runny nose, coughing, cold sores, boils, mild fever, warts/verrucae, pneumonia, bronchitis, sinusitis, sudden high fever, ear infection, diarrhea, meningitis, eye infection, sepsis, and long healing injuries. They were rated on a 5-point Likert-type scale (Never, Once or twice, Occasionally, Regularly, Frequently, with scores from 0 to 4 respectively). A high score reflects worse immune function.

Demographic information consisted of nine questions about participant and their child. Participants were asked to indicate their *gender, age, marital status, and occupation*, as well as to provide information about their child (*gender, age, diagnosis, and age at the time of diagnosis*). ASD types in the questionnaire were categorised using DSM-IV (APA, 2000) diagnoses (i.e. *Autistic Disorder, Asperger's Syndrome, Childhood Disintegrative Disorder, Rett Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified*). For diagnoses made using different classification system, participants were asked to tick *Other* and enter the exact diagnosis in the box.

Procedure

Support groups for parents whose children had an ASD diagnosis were contacted via e-mail. The e-mail explained the nature of the study, and asked to forward the invitation, together with an attached hyperlink, to the online survey. The information given in the link about the study was: "This study examines health of mothers of children with autism, and it consists of several short questionnaires that should take you about 30 minutes to complete. If you have any questions please do not hesitate to contact the researchers. Your participation in the study is entirely voluntary and you may withdraw at any time without penalty. All your data will be kept confidential. If you would like to take part in the study please click the link below.". Those parents who decided to take part in the study followed the link to an online surveying system, and were presented with further information about the purpose of the study. By clicking the *Next* button at the bottom of the page participants provided their consent to take part in the study. The questionnaires were presented in the following order – demographic information, PSQ, QRS-F, GHQ28, IDQ – and were followed by debrief after the submission of responses. The questionnaire package took about 20 minutes to complete. The study remained open for four months (March to June).

Results

Table 1 about here

Table 1 shows the mean scores for the mothers' perceived stress (PSQ), parenting stress (QRS), health-related QoL (GHQ), and immune function (IDQ), and the correlations between these variables. All of the variables had moderately-strong significant correlations with one another, with the relationships between the two stress scales (i.e., PSQ, QRS) being strong, as well as the relationships between these two scales and the GHQ scale.

Table 2 about here

The top panel of Table 2 shows the correlations between the mothers' perceived stress (PSQ), parenting stress (QRS), health-related QoL (GHQ), and immune function (IDQ) and the mothers' demographic characteristics: age (Pearson), and their partnered status and employment status (Point Biserial). These data show that only employment status impacted on parenting stress and health-related QoL (those out of work having higher parenting stress and lower QoL). The bottom panel of Table 2 shows the correlations between the PSQ, QRS, GHQ, and IDQ and the children's characteristics: age and age at diagnosis (Pearson), and gender (Point Biserial). None of these children's characteristics impacted on the parents' levels of stress or on the parent QoL or health variables.

Table 3 about here

Table 3 shows the mean scores for the mothers' perceived stress (PSQ), parenting stress (QRS), health-related QoL (GHQ), and immune function (IDQ), depending on the diagnosis of the child. Inspection of these data shows that mothers of children with a multiple diagnosis typically had worse parenting stress and health scores than those mothers of children with an autism diagnosis, and the lowest stress and best health scores were generally seen in mothers of children with an Aspergers' diagnosis. These differences were statistically reliable for parenting stress (QRS), and immune function (IDQ).

To determine which variables predicted the health-related QoL (GHQ) score a forwards stepwise multiple regression was conducted for both health-related QoL (GHQ) and immune function (IDQ) scores. This form of analysis was selected in order to identify the key predictors from the demographic variables relating to the family, which have been shown to predict these outcomes previously, and the two stress variables (general and parenting), that independently predict the target. In both of these analyses, the model reported is the last model that shows a significant increase in predictive validity relating to the target – adding additional variables after this did not significantly increase the reliability of the prediction of the outcome. The demographic information related to the families that was collected were entered: mothers' age, partnered status (coded 0 = no partner; 1 = partner), and employment status (0 = unemployed; 1 = employed), the child's age, gender (0 = female; 1 = male), and diagnosis (0 = autism; 1 = PDD:NOS), as well as the mother's perceived stress (PSQ) and parenting stress (QRS), were initially entered into the forwards stepwise regression. The last model that was significant, $F(3,112) = 6.21, p < .05, R^2 = .398$, contained three predictors: employment status (standardized beta = $-.137$; meaning that unemployed mothers has lower HRQoL), perceived stress (standardized beta = $.440$; meaning that the higher the perceived stress the worse the HRQoL), and parenting stress (standardized beta = $.200$; meaning that the higher the parenting stress the worse the HRQoL). The same analysis was also conducted

for immune function (IDQ), and this revealed that the last model to be significant, $F(1,113) = 10.89$, $p < .001$, $R^2 = .162$, had only one significant predictor: perceived general stress (standardized beta = .280; meaning that the higher the parenting stress the worse the immune function).

Discussion

The current report sought to establish if there were relationships between either general stress or parenting stress with health-related QoL or self-reported illness for mothers of children with ASD. Although there have been some explorations of physiological correlates of health (such as cortisol levels; e.g., Epel et al., 2004; Gallagher et al., 2009; Seltzer et al., 2010), and a few investigations of health-related QoL for this population (e.g., Allik et al., 2006; Hedov et al., 2000), there have been no direct investigations of directly reported immune function for mothers of individuals with ASD. It is also unclear if immune function or health-related QoL would be differentially impacted by the different forms of stress assessed.

The findings suggested that levels of general stress experienced by mothers of children with ASD were associated with a poorer health-related QoL and also with an increased experience of immune-related physical health problems. In contrast, the levels of parenting stress experienced by the mothers were associated only with worse health-related QoL, and were not with greater numbers of health symptoms. These findings replicate and extend the results of previous studies that have shown a relationship between general stress and health-related QoL, and also between parenting stress and health-related QoL (Allik et al., 2006; Hedov et al., 2000). However, the current study demonstrated that, although there was a relationship between general stress and symptoms related to ill health, this relationship was not found for parenting stress.

In terms of health-related QoL, the previous literature has shown that mothers of children with ASD report lower levels of health-related QoL than mothers of other groups of children (e.g., Allik et al., 2006; Hedov et al., 2000). The current results extend these findings to show that levels of parenting stress have a negative impact on health-related QoL. In addition to stress related to parenting, health-related QoL was also shown to be associated with perceived general stress levels, and also with employment status, which have also previously been noted to show association with QoL (Barrington et al., 2014; Marmot and Bell, 2012; Mugno et al., 2007).

In addition to the previously demonstrated impact of being a parent of a child with ASD on a range of physiological indices of future ill health (Epel et al., 2004; Gallagher et al., 2009; Seltzer et al., 2010), mothers of children with ASD also reported experiencing ill-health symptoms that were related to the level of daily stress that they experienced. The association between general stress and levels of ill health is complex, but has long been established (Dhabhar, 2014; Steptoe and Kivimäki, 2012, for overviews), and the current results suggest the same general negative impact of stress on health for mothers of children with ASD. A feature of the current results that deserves some comment is that physical symptoms were not strongly related to parenting stress per se.

Consideration of the pattern of data obtained in this and other studies, however, may offer a tentative account of this finding. A possibility is that the cumulative effect of parenting stress serves to blunt the daily pattern of cortisol levels that are typically noted (Dykens and Lambert, 2013; Lovell et al., 2012). These cortisol levels are usually high in the morning and become lower throughout the day (see Seltzer et al., 2010). However, mothers of children with ASD tend to show a reduced level of such cortisol activity in the morning (Dykens and Lambert, 2013; Seltzer et al., 2010), and often have lower levels of cortisol throughout the day, especially after prolonged exposure to child behaviour problems (Seltzer

et al., 2010). It is known that extended periods of stress eventually leads to lowered cortisol levels (see Miller, Chen, and Zhou, 2007), which can serve to reduce the negative impact of cortisol on the immune system (McEwen, 2004). So, while the disruption to cortisol activity (e.g., Seltzer et al., 2010) may serve to increase psychological problems (see Bremner, 1999; Miller et al., 2007), and potentially induce some neurological problems (Bremner, 1999; McEwen, 2004), any deleterious effect of disrupted patterns of cortisol on the immune system may be partially offset by reduced overall levels of cortisol (see Miller et al., 2007). Thus, due to the complex impact on cortisol levels of long-term exposure to the stress of child behaviour problems, physical symptoms may not be impacted overall. In contrast, whereas the parenting stress levels are relatively consistent and high for these mothers, daily stressors not related to parenting may be more variable – producing the more expected negative impact on health due to a lack of adaptation to these essentially unpredictable events.

There are a number of factors that could cause these levels of stress (and potential negative impact on cortisol levels). For example there is some previous evidence to suggest that levels of child behaviour problems impact negatively on health-related QoL in this population (Allik et al., 2006), which is known to be related to parenting stress (Lecavalier et al., 2006; Osborne and Reed, 2009b). In addition, issues such as employment status and levels of support (either from a partner or friends/family or professionals) may also impact on parents stress, and, consequently, on health. These factors will require further investigation to unpack the full impacts on health of parents of children with ASD.

Of course, there are a number of limitations to the current study, and these do need to be noted, and the suggestions made on the basis of the results treated cautiously. Clearly, the sample was recruited via an online means, which might have produced a bias in the type of person who participated. Information about the make-up of the individual online support

groups, and those who elected not to participate, would also have been useful (although difficult to collect through online means). This method of data collection limits the data to self-reports. While self-reports may be a strong measure of many of the current constructs, it would be helpful to take objective assessments of some of the variables as well. This would be particularly interesting in the context of relating some of the physiological indices that have been previously used to reports of illness experience. Moreover, the adoption of a longitudinal design would also help move away from the report of associations, to help establish temporal precedence between some of these events and reports. Although this would not, in itself, establish causation, it would be a first step in that direction. Moreover, it should be acknowledged that, in addition to general and parenting stress, there are a range of other factors that might also impact on these variables and on immune function, such as mental health, and further research could identify the nature of these relationships to determine the mechanisms driving the stress-health relationship. Such future studies could also include physiological measures, and interviews to collect information about parent perceptions of the key areas of health that are affected in order to guide the future work. Additionally, comparison groups of parents recruited in different ways (e.g., via a clinic) to investigate the generality of the results and to allow more detailed information about the sample composition. This would also allow data on whether the parents are accessing mental health services or having treatment for any mental health or other condition to be collected.

The basic findings from the current study, irrespective of the mechanisms that produce them, suggest that the levels of general and parenting stress experienced by mothers' of individuals with ASD do impact on their health. The economic cost of parenting an individual with ASD is already known to be high (Knapp et al., 2009), and factors which increase this cost, such as parental ill health should be taken seriously for the individual themselves and the services supporting them. Support to reduce both the general levels of

stress, like making the support systems easier to negotiate (Goin-Kochel, Mackintosh, and Myers, 2006) may reduce parents' stress and, subsequently, improve their health. In addition, helping the parents to manage their children may also impact on their parenting stress (Osborne and Reed, 2010), and reduce this impact on their health-related QoL.

In summary, the current data suggest that there is a link between some forms of experienced stress and both health-related QoL and reported illness symptoms in mothers of children with ASD. This extends the documentation and exploration of parental health in this population. That general stress and parenting stress differentially impact health-related QoL and physical symptoms suggests that the relationship between having a child with ASD, the impacts of such chronic stress on physiological responses, and the eventual impact on physical health is a complex matter that clearly deserves further investigation.

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Table 1: Mean (standard deviation) for mothers' (N = 122) perceived stress (PSQ), parenting stress (QRS), health-related quality of life (GHQ), and immune function (IDQ), as well as the Pearson correlations between them.

	Mean (SD)	QRS	GHQ	IDQ
PSQ	91.53 (16.35)	.699***	.613***	.355**
QRS	30.39 (9.68)		.528***	.344**
GHQ	35.46 (15.39)			.406***
IDQ	22.10 (10.91)			

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 2: Correlations between mothers' (N = 122) perceived stress (PSQ), parenting stress (QRS), health-related quality of life (GHQ), and immune function (IDQ) and mothers' characteristics (top panel) and child characteristics (bottom panel).

Mother	Age	Partner	Employed
PSQ	.019	-.031	-.083
QRS	-.002	.002	-.378**
GHQ	-.046	.029	-.203*
IDQ	.090	.060	-.104
Child	Age	Age at Diagnosis	Gender (0 = female, 1 = male)
PSQ	-.201*	.081	.046
QRS	-.095	-.112	-.028
GHQ	-.144	-.066	.141
IDQ	-.010	-.148	-.008

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 3: Means (standard deviations) for mothers' (N = 122), perceived stress (PSQ), parenting stress (QRS), health-related quality of life (GHQ), and immune function (IDQ) for different child diagnoses.

	Autism	Asperger	Multiple	<i>F</i>	<i>partial eta</i> ²
PSQ	91.73 (15.15)	90.18 (18.57)	94.95 (16.72)	<1	.007
QRS	31.53 (9.14)	27.36 (10.33)	33.08 (9.02)	2.97*	.048
GHQ	35.80 (14.03)	33.32 (16.98)	40.76 (17.52)	1.16	.019
IDQ	23.43 (10.84)	19.33 (10.76)	24.31 (10.53)	2.07*	.034

* $p < .05$; ** $p < .01$; *** $p < .001$