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Title of Paper: Predicting mental health and psychological wellbeing in mothers of children

with autism spectrum disorder: roles of intolerance of uncertainty and coping

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Abstract

Research has consistently shown that parents of children with autism spectrum disorder (ASD) are more likely to report chronic stress and symptoms of psychopathology when compared to parents of typically developing children and children with other psychological or physical conditions. Certain individual characteristics might either put parents at risk or allow them to cope more effectively under the strenuous conditions of raising children with neurodevelopmental conditions. Previous research has suggested that higher levels of intolerance of uncertainty and certain coping styles are associated with higher parental levels of anxiety and depression. The aim of this study is to characterize the way in which intolerance of uncertainty and coping (avoidant and problem-focused coping) predict mental health and psychological wellbeing in parents of children with ASD. Only mothers participated in this study. Fifty mothers (M_{age} = 44.28 years, SD_{age} = 6.58) of children with ASD completed questionnaires assessing anxiety and depression, psychological wellbeing, intolerance of uncertainty, and avoidant and problem-focused coping. The results from this study provides preliminary evidence that higher use of problem-focused coping but not avoidant coping and intolerance of uncertainty predicts psychological wellbeing. Furthermore, our observation of greater intolerance of uncertainty and higher use of avoidant coping predicting anxiety and depression supports previous research. The findings from this study have implications for the development of intervention programs to help improve the mental health and psychological wellbeing of parents.

Lay Summary: This research studied the factors that impact the mental health of parents of children on the autism spectrum. We found that mothers who are not comfortable with uncertainty, use more avoidant coping, and less problem-focused coping have poorer mental

health. Identifying these factors is a crucial first step in developing intervention programs to help improve the mental health of parents.

Keywords: autism, mothers, intolerance of uncertainty, coping, anxiety, depression, psychological wellbeing

Introduction

Research has consistently shown that parents of autistic children report higher levels of stress and more frequent and severe psychopathology symptoms when compared to parents of typically developing children and children with other psychological or physical conditions (Hayes & Watson 2013; Piven & Palmer 1999; Mazefsky et a. 2008; Kuusikko-Gauffin et al. 2013). Anxiety and depression are common, with up to 50% of parents reporting clinically significant anxiety (Bitska & Sharpley 2004; Mazefsky et al. 2008; Kuusikko-Gauffin et al. 2013) and up to 60% for depression (Bitska & Sharpley 2004; Carter et al. 2009). However, a significant proportion of parents does not show elevated affective symptoms. Some parents even report positive effects of raising a child with autism spectrum disorder (ASD). For example, King et al. (2012) interviewed parents of children with ASD or Down syndrome, and found that parents reported having an enriched family life and making a positive contribution to society through sharing personal experiences with other families.

In recent years, researchers have attempted to understand and target modifiable factors that cut across mental health conditions (transdiagnostic factors) in order to create effective interventions (Dozois et al. 2009). Across both normative and clinical samples as well as in parents of children with ASD, individual differences in the use of coping strategies and tolerance to uncertainty have been separately shown to be key factors behind anxiety and depression (e.g., Dugas et al. 1997; Hastings et al. 2005; Marx et al. 1992; Uljarević et al. 2016). Dysfunctional coping and intolerance of uncertainty are responsive to intervention and treatment programs targeting each construct, and these interventions have shown to improve mental health in several sample groups not associated with autism (e.g., Dugas & Ladouceur 2000; Peek & Melnyk 2010). Given the availability of effective treatment and support programmes for managing these two transdiagnostic factors, characterizing the nature of their

inter-relationship in predicting parental mental health is an important step in helping families to achieve positive outcomes.

Intolerance of uncertainty is a dispositional characteristic that leads people to experience aversive responses by the perception of uncertain or insufficient information (Carleton 2016). Intolerance of uncertainty has been shown to be a risk factor for generalized anxiety disorder (Dugas et al. 1997) and major depressive disorder (Miranda et al. 2008). Higher levels of intolerance of uncertainty has been shown to predict increased negative affective symptoms including anxiety, depression, and stress in two separate samples of parents of children with ASD (Su et al. 2017; Uljarević et al. 2016).

Coping has been defined as the "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman 1984, p. 141). Two distinctive and well-researched coping strategies are problem-focused and avoidant coping. Problem-focused coping involves defining the problem at hand, generating options to solve the problem, evaluating the benefits and costs of each option, choosing which option to implement, and implementing problem solving steps (Lazarus & Folkman 1984). In contrast, avoidant coping is aimed at escaping or avoiding the stress provoking situation without directly facing the problem (Folkman & Lazarus 1980). A systematic review found that parents of children with ASD use more avoidant coping strategies than those of typically developing children (Vernhet et al. 2019). Additionally, avoidant coping strategies are associated with elevated anxiety, depression, and stress levels (Hastings et al. 2005). In contrast, the use of problem-focused strategies lowered the stress levels of parents and improved their quality of life (Cappe et al. 2011; Wang et al. 2013).

Although associations of certain coping styles and intolerance of uncertainty with mental health are well established in parents of children with ASD, no research with this

group or any other group has examined the way in which both intolerance of uncertainty and coping might work together to predict anxiety and depression. Furthermore, the influence of these two factors on psychological wellbeing remains unexplored. Hence, the aim of the study is to characterize intolerance of uncertainty and coping (avoidant and problem-focused coping) in relation to mental health and psychological wellbeing in parents of children with ASD. Based on previous research findings, it was predicted that intolerance of uncertainty and avoidant coping style would be positively associated with and predict anxiety and depression. Given the lack of research on the relationships of intolerance of uncertainty and coping with psychological wellbeing, as well as of problem-focused coping style with anxiety and depression in parents of children with ASD, no hypotheses were generated for those relationships.

Methods

Participants

Participants were fifty mothers (M_{age} = 44.28 years, SD_{age} = 6.58) of children (M_{age} = 10.58 years, SD_{age} = 3.83) with ASD living in South Wales, UK. Although both mothers and fathers were encouraged to participate, only mothers participated. None of the mothers had a diagnosis of ASD. All children had been diagnosed with ASD by a community multidisciplinary team assessment according to DSM-IV-TR (American Psychiatric Association 2000) and ICD-10 (World Health Organisation 1993) criteria.

Procedure and measures

This study was approved by the Cardiff University School of Psychology Research Ethics Committee. Mothers were recruited via parent support groups and local schools. Mothers either completed and returned the questionnaire by post or completed it as part of a visit to the university. Parents were asked about their educational level, number of children, marital status as well as completing the following measures.

The *Hospital Anxiety and Depression Scale* (Zigmond & Snaith 1983) is a norm-referenced questionnaire used to assess anxiety and depression. It contains 14 self-report items, 7 items for anxiety subscale and 7 items for depression subscale.

The *Oxford Happiness Questionnaire* (Hills & Argyle 2002) is a 29-item scale designed to assess personal happiness. This questionnaire has been used as a measure of psychological wellbeing.

The *Ways of Coping Questionnaire* (Folkman & Lazarus 1988) is a 66-item measure used to capture a range of coping strategies. In this paper we focus on escape-avoidance and planful problem-solving.

The *Intolerance of Uncertainty Scale-12* (Carleton et al. 2007) is a 12-item short version of the original 27-item Intolerance of Uncertainty Scale (Freeston et al. 1994) designed to measure responses to uncertainty.

Results

Descriptive statistics of all measures are presented in Table 1. No data was missing, and no outliers were identified.

INSERT TABLE 1

Correlational analyses showed that higher use of avoidant coping and higher levels of intolerance of uncertainty were associated with higher levels of anxiety and depression but not psychological wellbeing (see Table 1). While higher use of problem-focused coping was associated with higher psychological wellbeing, the opposite pattern emerged for depression. Although the correlation between problem-focused coping and depression was no longer significant after Bonferroni adjustment, we included problem-focused coping for the

depression regression model. No significant association was found between problem-focused coping and anxiety.

A series of regression models showed that: (1) greater intolerance of uncertainty and higher use of avoidant coping uniquely and independently predicted anxiety (t = 3.21, p = .002, $\beta = .41$ and t = 2.67, p = .01, $\beta = .34$, respectively), with the full model accounting for 36.1% of variance (F = 12.45, p < .001); (2) greater intolerance of uncertainty, higher use of avoidant and lower use of problem-focused coping uniquely and independently predicted depression (t = 3.31, p = .002, $\beta = .39$, t = 3.23, p = .002, $\beta = .38$ and t = -2.94, p = .005, $\beta = -.33$, respectively), with the full model accounting for 48.2% of variance (F = 13.32, p < .001); and (3) higher use of problem-focused coping significantly predicted psychological wellbeing (F = 7.77, p = .008) accounting for 17.4% of variance.

Discussion

The mental health outcomes of parents of children with ASD are poor overall.

Identifying the transdiagnostic factors that influence parental mental health allows effective interventions and support programmes to be developed and enables families to achieve positive outcomes. Our study aimed to identify the unique contributions of problem-focused and avoidant coping and intolerance of uncertainty to mental health and psychological wellbeing in parents of children with ASD.

Only mothers participated in our study. As hypothesized, both greater intolerance of uncertainty and higher use of avoidant coping predicted anxiety and depression, which supports previous work in parents (Hastings et al. 2005; Su et al. 2017). We also found that lower use of problem-focused coping additionally contributed to depression but not anxiety. Although problem-focused strategies have been shown to lower stress levels in parents (Wang et al. 2013), no previous research in parents of children with ASD has examined the influence of problem-focused coping on anxiety and depression. In the non-ASD literature,

researchers have proposed that deficits in problem solving interact with stressful life events to lead to depression (D'Zurilla & Nezu 2001; Nezu 1987). Empirical evidence supports the role of problem solving in depression (e.g., Marx et al. 1992) and a meta-analytical review showed that problem-solving therapy is effective for reducing depressive symptomatology (Bell & D'Zurilla 2009). Given that parents experience high level of stress raising children with ASD (Hayes & Watson 2013), our observation of problem-focused coping predicting depression aligns with the problem-solving framework of depression. The disconnection between problem-solving coping and anxiety has also been identified in the non-ASD literature. For instance, Ladouceur et al. (1998) showed that problem-solving skills were not related to anxiety symptoms and did not differ between people with generalized anxiety disorder and nonclinical moderate worriers.

Only higher use of problem-focused coping was a significant predictor of psychological wellbeing in our sample of mothers. This finding somewhat relates to previous research observations – the use of problem-focused strategies has been shown to improve parents' quality of life (Cappe et al. 2011). The quality of life measure used by Cappe et al. (2011) was specifically designed for assessing the consequences of disability on the daily lives of parents and includes a wellbeing subdimension. Our study showed for the first time that neither avoidant coping nor intolerance of uncertainty were significant predictors of psychological wellbeing in mothers of autistic children. A longitudinal study has demonstrated that avoidant coping was a predictor of positive wellbeing in a sample of women post-miscarriage (Forbes-McKay et al. 2016). Given that the measures used by Forbes-McKay and colleagues were different to the ones used in this study and the unique and distinct circumstances of the two samples, it may not be appropriate to compare the results of these two studies. No study has explored whether or not intolerance of uncertainty is associated with psychological wellbeing in any population. Hence, further research is

needed to unravel the relationships of avoidant coping and intolerance of uncertainty with psychological wellbeing in parents of autistic children.

Limitations and future research

We would like to note a number of limitations of this study. Firstly, the study sample consisted of mothers of children with ASD because we were only able to recruit mothers and not fathers. Although looking at the whole family system and inclusion of fathers are important (Karst &Van Hecke 2012), it is challenging to engage fathers to participate in this kind of research (Wilson & Prior 2011). It would be interesting to investigate if coping and intolerance of uncertainty similarly predicted mental health and psychological wellbeing in fathers as in mothers. Secondly, the sample size of the study is relatively small, and all data were collected via a self-report questionnaire. Future studies should examine the relationships between these constructs in a larger, better characterized sample. Additionally, employment of a longitudinal design and comprehensive assessment of different coping strategies and distinct self-regulation domains such as executive functioning and emotion regulation to further characterize how child and environmental factors interact with these identified relationships is an important future avenue of research.

Conclusion

This is the first study to characterize the inter-relationship between coping, intolerance of uncertainty, mental health and psychological wellbeing in mothers of autistic children. The results from this study provide preliminary evidence that problem-focused coping but not avoidant coping and intolerance of uncertainty predicts psychological wellbeing. Furthermore, our observation of intolerance of uncertainty and avoidant coping predicting anxiety and depression supports previous research. The findings from this study have implications on the development of interventions and supports that aim to improve the mental health and psychological wellbeing of mothers of children with ASD.

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Table 1. Study variables (M, SD, range) with Pearson's correlations

Variable	М	SD	Range	HADS	HADS	Oxford	IU-12	Avoidant	Problem-
				Anxiety	Depression	Happiness		Coping	focused
						Questionnaire			Coping
HADS Anxiety	10.82	4.26	1–21						
HADS Depression	6.66	4.07	1–18	.65**					
Oxford Happiness	107.98	9.65	83–132	11	34*				
Questionnaire									
IU-12	25.88	9.02	12–46	.50**	.41**	08			
Avoidant Coping	7.28	4.98	0–17	.46*	.54**	02	.30*		
Problem-focused	9.38	3.81	0–16	10	30*	.42**	.20	10	
Coping									

Note: HADS: Hospital Anxiety and Depression; IU: Intolerance of Uncertainty. *p < .05, ** p < .003 (Bonferroni adjusted)