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**Exploring the moderating role of benefit finding on the relationship between child problematic behaviours and psychological distress in caregivers of children with ASD**

**Abstract**

Caregivers of children with ASD often find benefits associated with their caregiving role, and benefit finding predicts lower distress. Child problematic behaviours (CPB), which positively predict caregivers' distress, are perceived to be being less problematic, or more manageable, by caregivers who find benefits. Benefit finding therefore might mitigate the negative psychological impact of CPB. A sample of n=158 caregivers of children with ASD completed an online survey assessing benefit finding, CPB, and psychological distress. CPB positively, and benefit finding negatively, predicted caregivers' distress. Moderation effects however were not observed. Findings implicate increased CPB and lower benefit finding as risk factors for caregivers' psychological distress. Findings provide clearly definable targets for intervention.

**Keywords:** ASD; benefit finding; child problematic behaviours; moderation; psychological distress

The stress provoking effects of caring for a child with ASD have been widely reported. It has been revealed, in both cross sectional and longitudinal research, that caregivers of children with ASD, as compared to their non-caregiving counterparts, are more likely to report anxiety and depressive symptomology (Al-Farsi et al., 2016; Kennan et al., 2016; Lovell et al., 2014; Ruiz-Robledillo et al., 2013). In fact, in around 40% of cases, caregivers of children with ASD experience psychological symptoms resembling trauma (Stewart et al., 2017). Several review papers and meta analyses, and much qualitative research, have also reported on the negative impact of caring for a child with developmental disabilities (DD), including ASD, on psychological well-being (Hayes & Watson, 2013; Phelps et al., 2009).

Characteristics of the child with ASD, particularly their problematic behaviours, account for much of the variability in caregivers' psychological distress. For example, in several cross sectional studies, child problematic behaviours (CPB), particularly emotional behaviours, positively predicted reports of anxiety and depression, and other mental health difficulties, in caregivers of children with ASD (Lovell et al., 2016; McStay et al., 2013; Solomone et al., 2018). CPB have also been found, through their relationship with stress proliferation (i.e., the tendency for stressors to cause additional stressors), to positively, and prospectively, predict depressive symptomology in caregivers of children with ASD (Benson & Karlof, 2008). Moreover, in a recent meta-analysis, incorporating both cross sectional and longitudinal studies, the magnitude of the association between the problematic behaviours of the child with ASD and caregivers' psychological distress fell within the moderate range (Yorke et al., 2018). Studies involving caregivers of children with other additional complex needs, like intellectual disabilities and ADHD, conditions that share some clinical hallmarks of ASD, have also reported on the predictive contribution of CPB for caregivers' psychological distress (Lovell et al., 2015; Woodman & Hauser-Cram, 2012).

CPB have emerged as one risk factor for caregivers' psychological distress, but other characteristics of the care provider, such as more regular use of problem focused coping and greater access to support, have been identified for their protective effects (Lai & Oei, 2014; Lovell et al., 2012; Pin Ang & Loh, in press). The adaptive psychological effects of benefit finding, which refers to finding positive consequences (i.e., benefits) amidst stressful life experiences, have also been

observed in the context of caring for a child with ASD. Indeed, alongside the demands and challenges, caregivers of children with ASD regularly find benefits in their role, and these often include increased feelings of relationship satisfaction, greater appreciation for life and loved ones, and greater feelings of empathy and compassion (Bekhet et al., 2017; Hillman & Anderson, 2019; Sim et al., 2019).

Benefit finding, like problem focused coping and social support, has been recognised for its stress mitigating properties. For example, in several correlational studies involving caregivers of children with DD (including ASD), an inverse association was observed between benefit finding, or closely related constructs such as positive reframing, and distress outcomes, like anxiety and depression (Bekhet et al., 2018; Cassidy et al., 2014; Cheshire et al., 2012; Kayfitz et al., 2010).

Whether benefit finding, known for its stress alleviating properties, might mitigate the negative impact of CPB on caregivers' psychological well-being has not been explored. This was the aim of the current study. Several lines of evidence converge to suggest this might be the case. For example, benefit finding, in addition to its positive psychological impact for the care provider, has been shown to influence quality of life outcomes for the child with ASD (Zhou et al., 2014). For example, caregivers' reported benefits positively predict prosocial behaviours, and inversely predict problematic behaviours, in the child with ASD (Bekhet et al., 2016). Moreover, in several qualitative studies and literature reviews, caregivers have highlighted the value of resourcefulness for coping with caregiving related challenges, like CPB (Bayat, 2007; Bekhet et al., 2012; Foo et al., 2015), and benefit finding has been shown to positively predict resourcefulness in caregivers of children with ASD, and in other caregiving populations (Bekhet et al., 2013; 2018). Finding benefits amidst the negative sequelae of the caregiving experience has also been associated with increased social support, and socially supported caregivers of children with ASD, in addition to reporting lower distress (Lovell et al., 2012), feel better equipped to manage caregiving related challenges, like CPB (Freuler & Baranek, 2016). Moreover, in studies involving other caregiving groups, such as caregivers of adults with chronic illness, benefit finding moderated the relationship between caregiving related burden and psychological distress. That is, caregivers' burden scores, dictated in part by the problematic behaviours of the care recipient, predicted depressive symptomology at lower and medium, but not higher, levels of benefit finding. In other words, higher levels of benefit finding buffered against the

negative psychological consequences of caregiving related burden (Walker et al., 2016). Moreover, it has been revealed, in studies involving caregivers of children with ASD, that more regular use of cognitive reframing, a coping technique closely related to benefit finding, attenuates the prospective, positive relationship between child externalising (i.e., behavioural) problems and psychological distress (Benson et al., 2014).

This study, informed by the research above, will explore the main effects of CPB and benefit finding on psychological distress, and the moderating impact of benefit finding on the CPB-distress relationship, in caregivers of children with ASD. We hypothesised that CPB will positively, and benefit finding will negatively, predict psychological distress, and benefit finding will buffer against the negative psychological impact of CPB. In particular, we hypothesised that CPB would positively predict caregivers' psychological distress at lower and medium, but not in the context of higher, levels of benefit finding.

## **Methods**

### **Participants & procedure**

A priori power analysis indicated that  $n=77$  participants would be needed to provide adequate power (80%;  $\alpha = 0.05$ ) to detect a moderate effect size ( $f^2 = 0.15$ ). Here, by posting adverts on caregiving information and support groups of social media sites, a sample of  $n=158$  participants, composed of both UK and international (USA and Australia) caregivers, was recruited. To be eligible to take part, participants had to be aged  $>18$  years of age, caring for a child, aged  $>3$  years and living at home full time, with ASD (as clinically diagnosed by GP, paediatrician, or other health care providers, e.g., psychologist/psychiatrist), and not caring for another person, like a parent, partner, friend, or other, with chronic illness. Caregivers were asked to complete self-report measures of child problematic behaviours, benefit finding and psychological distress, and to provide basic socio-demographic and lifestyle information, as well as information about the child with ASD, via online survey. The institutional ethics committee approved the study, and all caregivers provided informed consent. No financial recompense was offered.

Data was removed for  $n=4$  participants who failed to provide responses to at least one of the questionnaires. Mahalanobis distance values, calculated using  $\chi^2(2, n=10) = 9.21, p < .01$ , were estimated for each of the study variables to screen for multivariate outliers, and this resulted in the exclusion of  $n=2$  participants with values  $>9.21$ . Statistical analysis therefore was conducted on a final sample of  $n=152$ . Mean age of the sample was 40.7 years (range: 27- 65 years). The majority were female (95%), of white ethnicity (93%), employed, full or part time (56%), in a relationship, i.e., partnered (79%), and with at least two children (81%). Caregivers exercised an average three times per week (range: 0-16), most were non-smokers (85%), and consumed few alcoholic drinks per week ( $M = 2.9, SD = 4.7$ ). Mean age of the child with ASD was 10.1 years (range: 1-22 years), and most were described as high functioning (73%). A small number of caregivers (13%) reported caring for two or more children with ASD.

## Measures

### Potential confounds

Data was collected on a range of socio-demographic (e.g., gender, age, relationship status, number of children) and lifestyle (e.g., exercise, smoking, alcohol) variables, and information about the child with ASD was collected (e.g., age, functional status), to safeguard against spurious relationships emerging between predictor and outcome variables.

### Child problematic behaviours

The Strengths and Difficulties Questionnaire (SDQ), a 25 item self-report measure using a three point Likert type scale (0 = not true - 2 = certainly true), was used to quantify the problematic behaviours of the child with ASD (Goodman, 1997). The SDQ assesses child behaviours across several subscales, four that assess problem behaviours (emotional, conduct, peer problems, and hyperactivity), and one that captures prosocial behaviour. A total score for problematic behaviours, calculated by summing responses across the four problem behaviour subscales, range from 0-40, with higher scores reflecting more behaviour problems. The SDQ was reliable ( $\alpha = .86$ ) in other recent studies (Lovell et al., 2015). Internal consistency in the current sample was adequate ( $\alpha = .65$ ).

## Benefit finding

The 17 item Benefit Finding Scale (BFS), originally designed to assess the benefits associated with living with cancer, was modified to capture the benefits of caring for a child with ASD (Carver & Antoni, 2004). Each item, and there are 17 items total, is prefixed with the statement ‘having had cancer has’ (e.g., led me to be more accepting of things, brought my family closer together, taught me to be patient), and this prefix was changed in the current study to read ‘caring for a child with ASD has’. The items were not modified, only the prefix. The questionnaire uses a five point Likert type scale ( $1 = \text{not at all}$ ,  $5 = \text{extremely}$ ) to assess benefit finding. Total scores, calculated by summing across all 17 items, range from 17-85, with higher scores reflecting more benefits. The BFS, modified for use with caregivers, has been shown to have good internal consistency (all alphas  $> .89$ ) in other recent studies (Ekas et al., 2015; Gardner et al., 2017; Slattery et al., 2017), and psychometrics in the current study were good ( $\alpha = .87$ ).

## Psychological distress

The 14 item Hospital Anxiety and Depression Scale (HADS), which incorporates a four point Likert type scale ( $0 = \text{never}$ ,  $3 = \text{considerable}$ ), was used to assess psychological distress (Zigmond & Snaith, 1984). Seven items assess anxiety (e.g., I feel tense or wound up), and seven measure depression (e.g., I feel as if I am slowed down). Total subscale scores, calculated by summing across the seven respective items, range from 0-21, with higher scores reflecting greater anxiety or depression. The HADS has been shown to be a consistently reliable measure, and this was the case in the current sample ( $\alpha = .76$ ).

## Statistical Analysis

Bivariate and, for categorical data, point bi-serial correlations were used to assess whether caregivers’ anxiety and depression scores might be related to socio-demographic and lifestyle variables, and characteristics of the child with ASD. The SPSS PROCESS macro, model 1, with bootstrapping (5000 iterations), as per Hayes (2012), was used to explore the extent to which caregivers’ reports of anxiety and depression might be predicted by CPB and benefit finding, and their

interaction. For more information on this method, or the bootstrapping procedure, please refer to Hayes (2013).

## Results

### Preliminary Analysis

Caregivers' reports of anxiety (all  $ps > .10$ ) and depression (all  $ps > .09$ ) were unrelated to any sociodemographic or lifestyle variables, or characteristics of the child with ASD. CPB were positively associated with anxiety ( $r = .27, p < .001$ ) and depression ( $r = .29, p < .001$ ), but unrelated to benefit finding ( $r = -.03, p = .68$ ). Benefit finding, while inversely related to depression ( $r = -.20, p = .02$ ), was unrelated to anxiety ( $r = -.06, p = .42$ ). Table 1 displays relationships between study variables.

INSERT TABLE 1 HERE

### Moderation Analysis

For anxiety, the regression model, which included CPB, benefit finding, and their interaction, accounted for 8% of the variability ( $F(3,148) = 4.44, p < .01$ ), with CPB ( $\beta = .24, t = 3.32, p < .001$ ), but not benefit finding ( $\beta = -.03, t = -.77, p = .45$ ), emerging as a unique predictor. Benefit finding did not interact with CPB to predict anxiety ( $\beta = .006, t = .98, p = .33$ ). For depression, the regression model accounted for 12% of the variability ( $F(3,148) = 6.85, p < .001$ ), with CPB ( $\beta = .23, t = 3.54, p < .001$ ) and benefit finding ( $\beta = -.07, t = -2.47, p = .02$ ), but not their interaction ( $\beta = .005, t = .93, p = .36$ ), uniquely predicting caregivers' depression scores.

These data suggest anxiety and depression were greater for caregivers of children with more problematic behaviours, and depression was greater for caregivers who reported fewer benefits.

Benefit finding not did not moderate the psychological effect of CPB.

## Discussion

This study explored the moderating role of benefit finding on the CPB-distress relationship in caregivers of children with ASD. Here, caregivers of children with more problematic behaviours were



more likely to report anxiety and depression. Findings are commensurate with other correlational studies that have reported on the positive relationship between CPB and caregivers' anxiety and depression, and with qualitative studies that have implicated CPB as one risk factor for caregiving related distress (Hutchison et al., 2016; Ludlow et al., 2011; Salomone et al., 2018; Yorke et al., 2018). Here, as expected, benefit finding was inversely associated, albeit rather negligibly, with caregivers' psychological distress. This finding, of reduced depressive symptomology in caregivers who report greater benefit finding, resonates with several other studies involving familial caregivers, and with studies that observed palliative effects of benefit finding on psychological distress in other chronically stressed populations (Bekhet et al., 2012; 2018; Cassidy et al., 2014; Cheng et al., 2017; Kayfitz et al., 2010). Here, of the two psychological indices, it was depression, not anxiety, that was related to benefit finding. This was an interesting finding, especially in light of previous research, some involving caregivers, that reported on the predictive value of benefit finding for both of these psychological indices (Mei et al., 2018; Wang et al., 2015). Other studies however, most notably a meta-analysis by Helgeson et al (2006), revealed that benefit finding, while associated with reduced depressive symptomology, was unrelated to feelings of anxiety. Moreover, in studies involving caregivers of children with ASD in particular, benefit finding, rather than being unrelated to anxiety, emerged as one positive predictor (Samios et al., 2009). The heterogeneity of these results might be explained, to some degree, by methodological variations. Indeed, some studies used a modified version of the BFS, as we did in the current study, while others used alternative, self-report assessments, like the BFS-PCAS. Moreover, in several of these studies, benefit finding was broken down into sub-categories, like new possibilities and spiritual growth, and it was these sub-categories, and not global benefit finding scores, such as those used in the current study, that predicted distress outcomes.

Findings reported here have clear, clinically relevant implications. Indeed, interventions that help caregivers find benefits amidst the negative sequelae of the caregiving experience, and help them cope better with the problematic behaviours of the child, might promote positive psychological adjustments. This would appear to be an important point given that caregivers' psychological distress can worsen with time (Glidden et al., 2003), and predicts various quality of life outcomes for the child

(Hutchison et al., 2016). It should be noted however, that caregivers' psychological well-being has also been found to improve with time (Benson & Karlof, 2008), and that findings in this respect are mixed. Encouragingly, CPB appear to be amenable to improvement via intervention. For example, structured family therapy (SFT), by increasing caregivers' feelings of support and self-efficacy, and their use of proactive coping skills, was effective for reducing problematic behaviours in children with ASD (Brockman et al., 2016). Parent skills training (PST), in which caregivers are taught, with clinical guidance, to recognise antecedents of CPB, was also found to be advantageous for reducing CPB and, in turn, improving caregivers' psychological well-being (Feldman & Werner, 2002). The adaptive psychological effects of benefit finding interventions have also been observed in the context of the caregiving experience. Indeed, caregivers of children with ASD who wrote for 15 minutes per day, for three consecutive days, about the benefits of the caregiving experience were less likely, as compared with a control group, to satisfy clinical criterion for borderline mood disorder three months later (Lovell et al., 2015). Encouragingly, for caregivers of children with ASD that might struggle to find benefits associated with their experience, psychological interventions, particularly positive thinking training programmes (PTT), have been found to be advantageous for increasing benefit finding, as well as positive thinking (Bekhet, 2017). How the positive psychological changes fostered by these interventions predict quality of provided care might provide a foundation for future research.

Here however, against expected findings, benefit finding did not moderate the relationship between CPB and psychological distress. This was unexpected, as benefit finding has been associated with lower levels of psychological distress in caregivers of children with ASD, and was found to buffer against the negative impact of caregiving related burden, of which CPB were included, on psychological functioning (Walker et al., 2016). Failure to observe moderation effects in the current study might be explained, at least to some degree, by the kinds of benefits caregivers are finding. That is, caregivers typically report finding benefits such as greater compassion and empathy, and deeper appreciation for life and loves ones, and greater family cohesion (Hillman & Anderson, 2019; Sim et al., 2019). In previous studies with caregivers of children with ASD, and in the current study, finding these kinds of benefits was associated with lower depressive symptomology (Bekhet et al., 2012; Cheshire et al., 2012). These kinds of benefits however, while effective for alleviating feelings of

depression, are likely to be ineffective in helping caregivers manage the kinds of problematic behaviours, like tantrums, aggressive and self-injurious behaviours, that characterise ASD. This might explain why, in the current study, benefit finding, while related to lower levels of depressive symptomatology, was unrelated to CPB, and did not buffer against the detrimental effect of CPB on caregivers' psychological well-being. Indeed, to cope with the problematic behaviours of the child with ASD, caregivers often used proactive, problem-focused strategies such as meticulous planning and organisation, structured, well-rehearsed routines, and information and help seeking, and not benefit finding (O'Nions et al., 2018). Future studies therefore, might explore whether coping behaviours, particularly the use of problem-oriented strategies, such as those described above, might safeguard against the negative psychological impact of CPB. Indeed, it has been reported, in several qualitative studies, that problem oriented strategies, like well-rehearsed routines and planning, and information seeking (i.e., about the disorder), are fundamental for coping with the stress of caring for a child with ASD, and for managing CPB in particular (Kuhaneck et al., 2010). Interventions that incorporate and teach coping behaviours, like use of structure, planning and routines, are, for many practitioners, the preferred way to treat CPB in children with ASD (Campbell, 2003). Moreover, caregivers who use greater problem focused coping behaviours, in addition to being less susceptible to psychological distress, have reported feeling more confident about providing good quality care for the child (Lovell & Wetherell, 2015). It might be that caregivers who use these kinds of coping behaviours, because they have proactively sought information about the behavioural problems associated with the disorder, and have formulated structured routines to minimise them, are less likely to experience CPB, or are better equipped to manage them when they do occur. As such, the relationship between CPB and caregivers' distress might be attenuated in the context of more regular use of these kinds of proactive coping behaviours, and future studies might explore this.

Alternatively, positive reframing, closely related as a construct to benefit finding, might have been a more appropriate moderator. Indeed, positive reframing, the process of positively restructuring the way negative events (e.g., CPB) are appraised, has been found, in studies involving caregivers, to be associated, longitudinally, with lower distress, and to attenuate the negative psychological impact of child externalising (i.e., problematic) behaviours (Benson et al., 2014). Here, as a construct closely

related to positive reframing, benefit finding, while associated with lower distress, did not safeguard against the negative psychological impact of CPB. This might be explained by the fact that caregivers, rather than being asked to positively reappraise CPB, and find benefits, as they would with positive reframing, were asked to find benefits associated with the global caregiving experience. These kinds of non-specific benefits, like increased compassion and feelings of family cohesion, while effective for alleviating distress, were unrelated to CPB and, without changing caregivers' appraisals of CPB, ineffective for mitigating the CPB-distress relationship.

Finding reported here should be tempered by study limitations. First, the cross sectional nature of the study does not allow for making casual inferences and, with previous research reporting bi-directional relationships between CPB and caregivers' distress (Hutchison et al., 2016), longitudinal studies are needed to tease apart the direction of these effects. Second, by virtue of the recruitment method (i.e., online support groups), caregivers might have been fairly well supported, and this is not representative of the wider caregiving population (Kim et al., 2018). As such, and with social support predicting both CPB and benefit finding (Pakenham et al., 2004), findings reported here should be interpreted with a degree of caution. Moreover, also related to recruitment, we recruited a rather homogenous sample, with 73% of children being described as high functioning. Caregivers' psychological well-being has been found to vary according to the functional status of the child, and CPB, which tend to be less frequent in high functioning children, might mediate this effect (Andersen et al., 2017). Findings reported here therefore might not be generalised to caregivers of lower functioning children. Third, child ASD and functional status was confirmed by parent report only, and despite studies finding parent reports to be reliable (Rosenberg et al., 2009), more objective assessments, incorporating standardised measures, should be encouraged, as should recruiting a more balanced ratio of female: male caregivers. Finally, the SDQ, while used in recent studies, and with similar samples, might not be an optimum measure of CPB, and the lower than expected alpha value in the current study is to be acknowledged. Other, more sample specific measures, like the Behaviour Problems Inventory-01 (BPI-01), might be incorporated into future studies looking to explore the impact of CPB on caregivers' psychological well-being, and the role of moderating factors.

In conclusion, caregivers of children with more problematic behaviours were more likely to report anxiety and depression, and depressive symptomology was higher in caregivers who reported finding fewer benefits amidst the negative sequelae of the caregiving experience. Benefit finding, despite being inversely associated with caregivers' depressive symptomology, did not mitigate the psychological consequences of CPB. Caregivers of children with more problematic behaviours, and those who report finding fewer benefits from the caregiving experience, might be particularly appropriate targets for psychological intervention.

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Table 1.

Means and standard deviations for, and relationships between, study variables

	1	2	3	4	Mean	SD	Range
1. CPB	-				22.8	5.4	8-35
2. Benefit finding	-.03	-			60.0	11.7	31-82
3. Anxiety	.27**	-.06	-		11.3	4.9	0-21
4. Depression	.29**	-.20*	.60**	-	9.0	4.5	0-21

**Acronyms:** CPB: child problematic behaviours

\* $p < 0.05$ , \*\* $p < 0.01$