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FINDING BENEFIT AND FEELING STRAIN IN PARENTING A CHILD WITH
AUTISM SPECTRUM DISORDER

A Thesis

Submitted to the Graduate Faculty of the
University of South Alabama
in partial fulfillment of the
requirements for the degree of

Master of Science

in

Psychology

by

Haley C. Adams

B.S., Kent State University, 2019

May 2022

TABLE OF CONTENTS

LIST OF TABLES	iv
LIST OF FIGURES	v
LIST OF ABBREVIATIONS.....	vi
ABSTRACT.....	vii
CHAPTER I.....	1
CHAPTER II.....	5
2.1 CPB and Caregiver Distress.....	5
2.2 Caregiver Strain.....	7
2.3 Resilience and Positive Cognitions.....	9
2.3.1 Caregiver Benefit Finding	10
CHAPTER III	13
3.1 Aims and Hypotheses.....	13
CHAPTER IV	16
4.1 Design.....	16
4.2 Participants	16
4.3 Measures.....	17
4.3.1 Demographic Information	17
4.3.2 Child and Parental Efficacy Scale	18
4.3.3 Depression Anxiety Stress Scale	18
4.3.4 Caregiver Strain Short Form.....	19
4.3.5 Caregiver Benefit Scale	20
4.4 Data Analysis	21
CHAPTER V	24
5.1 Participant Characteristics.....	24
5.2 Preliminary Analyses	24
5.3 Hypothesis 1: Mediation Testing	25
5.4 Hypothesis 2: Moderation Testing	26
5.5 Hypothesis 3: Moderated Mediation Testing.....	27

CHAPTER VI	29
6.1 Specific Aim 1: Caregiver Strain as a Mediator	30
6.2 Specific Aim 2: Caregiver Benefit Finding as a Moderator.....	31
6.3 Specific Aim 3: Moderated Mediation.....	32
6.4 Limitations	33
6.5 Future Directions.....	34
REFERENCES	36
BIOGRAPHICAL SKETCH	48

LIST OF TABLES

Table	Page
1. Means, Standard Deviations, and Correlations for Study Variables.....	25

LIST OF FIGURES

Figure	Page
1. Moderated Mediation of CPB, Caregiver Strain, CBF, and Caregiver Distress.....	15
2. Mediation of CPB, Caregiver Strain, and Caregiver Distress.....	26
3. Moderation of Caregiver Strain and Caregiver Distress by CBF.....	27
4. Moderated Mediation of CPB, Caregiver Strain, CBF, and Caregiver Distress.....	28

LIST OF ABBREVIATIONS

ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
CAPES-DD	Child and Parent Efficacy Scale- Developmental Disability
CBF	Caregiver Benefit Finding
CBS	Caregiver Benefit Scale
CPB	Child Problem Behaviors
CGSQ-SF	Caregiver Strain Questionnaire-Short Form
DASS-21	Depression Anxiety Stress Scale-21
IAN	Interactive Autism Network
SDQ	Strengths and Difficulties Questionnaire

ABSTRACT

Adams, Haley C., M.S., University of South Alabama, May 2022. Finding Benefit and Feeling Strain in Parenting a Child with Autism Spectrum Disorder. Chair of Committee: Kimberly R. Zlomke, Ph.D., BCBA-D.

Female caregivers of children with Autism Spectrum Disorder, often report higher levels of stress, anxiety, and depression which are often related to increased levels of caregiver strain, as well as the frequency and severity of child problem behaviors (CPB). Despite negative aspects of caring for a child with ASD, caregivers have also found benefit. The current study extended the caregiver benefit finding (CBF) and caregiver strain literature by exploring the role that these variables play in the mental health of female caregivers of children with ASD ($n = 259$), by assessing caregiver strain as a mediator between CPB and caregiver distress, examining CBF as a moderator between caregiver strain and distress, and assessing a moderated mediation of CPB, caregiver strain, caregiver distress, and CBF. Results suggest that caregiver strain is a significant mediator between CPB and caregiver distress, however CBF was not found to be a moderator, and thus the moderated mediation was not supported. CBF was a significant predictor for caregiver distress. Findings inform theoretical applications within the ASD sample and provide implications for future research in the development of interventions to enhance functioning in female caregivers.

CHAPTER I

STATEMENT OF PROBLEM

Stress related to caregiving for a child is often a ubiquitous experience, however caregivers of children with neurodevelopmental disorders often face higher stress levels than parents of typically developing children. Specifically, rearing a child with ASD is correlated with higher levels of parental stress and mental distress than parents of typically developing children (Baker-Ericzen et al., 2005; Craig et al., 2016; Estes et al., 2009; Hayes & Watson, 2013; McStay et al., 2014). Though several effective interventions and treatments exist for ASD currently, a deeper understanding of the caregiving experience is needed.

Many studies have looked at the relationship between increased child problem behaviors (CPB) in children with ASD in relation to caregiver psychological distress, such as stress, depression, and anxiety (Baker et al., 2002; Bitsika & Sharpley, 2004; Glasberg et al., 2006; Hamlyn-Wright et al., 2007; Yorke et al., 2018). CPB are likely a significant contributor to caregiver distress, however, it is unlikely that these behaviors alone are responsible for the increased distress levels. Caregiver strain, also referred to in the literature as “caregiver burden”, is typically thought of as the perceived negative effects of parenting a child with a disability (Brannan et al., 1997). Caregiver strain includes both externally negative effects on various aspects of daily life, such as financial burden and daily routine disruption, as well as internal, emotional negative consequences of caregiving, such as feelings of embarrassment and resentment. Caregiver strain has been found to mediate the relationship between CPB and caregiver distress. Furthermore, increased CPB has been found to be predictive of higher levels

of caregiver strain (Bradshaw et al., 2020; Green et al., 2016). There exists a copious amount of literature on the negative effects of raising a child with ASD, however, many families have been found to be resilient in the face of such adversity.

Despite negative aspects of caring for a child with ASD, caregivers have also found benefit. Among the literature on positive cognitions is an emerging construct known as caregiver benefit finding (CBF). This is typically thought of as the positive impact that caregivers feel when caring for a child with developmental disabilities (Amtmann, Liljenquist, et al., 2020). CBF includes caregiver feelings of appreciation for life, finding new strengths in themselves, feeling that caregiving has made them a better person, feeling more connected to those around them, etc. (Amtmann, Liljenquist, et al., 2020; Kim et al., 2007). This construct has been theorized as a type of positive cognition, which has been found to protect against the negative aspects of parenting a child with ASD (Bekhet, 2014; Smith et al. 2008; Weiss et al., 2012).

It is necessary for researchers to explore parental coping strategies that utilize positive cognitions, such as CBF, because this allows researchers to shift away from placing all expectations of change on the child (Zhou & Yi, 2014). In a recent study, Lovell and Wetherell (2020) examined the moderating role that benefit finding has been predicted to have on the relationship between CPB and distress in caregivers of children with ASD. Lovell and Wetherell (2020) did not find CBF to be a moderator, however their research was limited by an imprecise measure of CPB, and overlooking the role of caregiver strain in its contribution to caregiver distress. The statement of the problem which remains to be answered is whether parents of children with ASD who display more CPB experience greater strain, and whether this leads to increased distress levels, which can be decreased with CBF. The current study aims to fill this

gap and extend the literature by addressing the relationship using a moderated mediation analysis.

The purpose of the present study is to examine the effects of CPB, in children with ASD, on caregiver distress, and caregiver strain, as well as assess the effects of CBF on the relationship between caregiver strain and caregiver distress. The first aim of this study is to examine the relationship between CPB and caregiver distress, with caregiver strain as a mediator to this relationship. Caregiver strain will be measured in terms of objective strain, or the external burdens on caregivers of children with ASD (i.e., disrupted routines). Caregiver distress will refer to caregiver experiences of symptoms of depression, anxiety, and stress.

The second aim of this study is to assess the relationship between caregiver strain and caregiver distress, with this association moderated by CBF, in caregivers of children with ASD.

The third aim of this study is to assess both above relationships in combination, or a moderated mediation of the relationship between CPB and caregiver distress, with caregiver strain mediating this relationship, and CBF moderating the relationship between caregiver strain and caregiver distress.

These findings could direct clinicians towards more effective coaching strategies for parents of children with ASD, particularly those displaying CPB. If CBF can protect against parental strain, then it would be imperative that CBF be integrated into current methods of treatment. It is important to fully explore coping strategies that utilize positive cognitions, such as CBF, because it allows researchers to shift away from focusing solely on the negative aspects of parenting children with ASD, and explore solutions for parents to alleviate distress. This study further adds to this literature area by expanding upon research done by Lovell and Wetherell (2020), using more precise measures and assessing caregiver strain as a mediator between CPB

and caregiver distress. This study helps further flesh out the experience of the caregiver of a child with ASD. Learning ways in which parents can lower distress levels not only benefits the parent, but the child they care for as well. Thus, research in this area is essential for lessening the suffering of those within the ASD community, and their loved ones.

CHAPTER II

LITERATURE REVIEW

Autism spectrum disorders (ASD) are a set of neurodevelopmental disorders that are associated with impairments within two major areas: social-interaction and communication, as well as restricted and repetitive patterns of behaviors and interests (American Psychiatric Association, 2013). The Centers for Disease Control (CDC) reports the most recent autism prevalence rate as 18.5 per 1,000, or 1 in 54, children aged eight years. This prevalence rate has been increasing over the last few decades (Maenner et al., 2020).

ASD is seen as a spectrum disorder because there is a broad range of social deficits and behaviors that can be seen in those with ASD. These symptoms can range in severity, and it has been found that higher levels of ASD symptoms are related to higher levels of parental distress (Benson, 2006), findings which are consistent between both mothers and fathers of children with ASD (Davis & Carter, 2008). Studies have identified several possible risk factors that could be contributing to this increase in distress, including but not limited to, child behavioral and emotional problems, the financial burden of treatment, and co-morbid mental health problems (Giovagnoli et al., 2015).

2.1 CPB and Caregiver Distress

Children with ASD are more likely to display CPB than their typically developing peers, thus, caregivers of children with ASD often must learn to cope with an increase in CPB (Dykens,

2000; Hastings, 2002). Common CPB that appear in children with ASD include hyperactivity, tantrums, stimming, impulsivity, restricted eating, sleep problems, self-injurious behavior, and physical aggression (Curtin et al., 2015; Hayes & Watson, 2013). These behaviors can range in severity and variety. Many possible explanations have been given for why children with ASD are more likely to display problem behaviors, including genetic, neurological, and socio-economic factors (Dykens, 2000).

Research has consistently found that problem behaviors contribute to increased stress levels in caregivers (Baker et al., 2002; Baker et al., 2003; Lecavalier et al., 2006). Externalizing CPB—like physical aggression and hyperactivity—are found to be some of the most prominent factors contributing to parental stress (Benson, 2006; Donenberg & Baker, 1993). Giovagnoli et al. (2015) found that parents of children with ASD experience higher stress levels than parents of typically developing children, and that children with ASD show more behavioral and emotional problems. Additionally, it was shown that these behavioral problems were strong predictors of parental stress, while stress related to a parent–child dysfunctional relationship was related to daily living and communication skills as well as cognitive abilities. Heightened levels of stress, however, are not the only difficulty caregivers of children with ASD experience.

Along with higher parental stress levels, caregivers of children with ASD also report increased levels of anxiety and depression, and less confidence in parental ability compared to caregivers of typically developing children (Bitsika & Sharpley, 2004; Glasberg et al., 2006; Hamlyn-Wright et al., 2007). A systematic review of this literature area revealed that higher levels of parental distress had stronger relationships with child emotional and behavioral problems, an association that remained consistent with both internalizing and externalizing difficulties in children with ASD (Yorke et al., 2018). These findings supported a previous meta-

analysis on parental distress within the general population, with increased CPB predicting increased maternal depression (Goodman et al., 2011).

With increasing evidence that CPB are related to parental distress, researchers have begun to further explore this relationship. Rezendes and Scarpa (2011) found that among mothers of children with ASD, CPB was related to increased parental stress, which accounted for decreased parental self-efficacy, all while controlling for ASD severity in terms of functioning. In addition, they found that lower parental self-efficacy partially accounted for increased anxiety and depression. This study underscores an important ideal that the current study further explores: the mediating role of caregiver strain in the relationship between CPB and caregiver distress.

2.2 Caregiver Strain

While CPB has been found to significantly contribute to caregiver distress, it is unlikely that these behaviors are themselves directly responsible for the increased distress levels.

Caregiver strain is thought to be a potential mediator between the relationship between CPB and caregiver distress (Brannan & Heflinger, 2001; Hamlyn-Wright et al., 2007; Sales et al., 2004).

Caregiver strain is considered to come in two forms: objective and subjective strain. Objective strain is the caregiver's perception that parenting their child outwardly has negative effects on various aspects of day-to-day life, such as increased financial burden and daily routine disruption. On the other hand, subjective strain describes the internal, emotional negative consequences of caregiving, such as feelings of worry and fatigue (Brannan & Heflinger, 2001).

As previously discussed, the term "caregiver strain" is often used interchangeably with "caregiver burden", because these terms represent the same constructs. However, for the purpose

of this study, the term “caregiver strain” will be used primarily. Additionally, it is important to distinguish between caregiver strain and caregiver distress, as the two terms are often confused. Brannan and Heflinger (2001) assessed the distinction between caregiver strain and caregiver distress by applying an ABCX model. In this model, child symptoms and life stressors (A) pile up, leading families to reach out to resources (B), while perceptions of these events (C) are formed (i.e., attributions of cause, expectations for family members), all of which would lead to both caregiver strain and caregiver distress (X), separately. Using data from 514 families, they found that this model was supported—caregiver strain and distress are related, but markedly separate constructs. Moreover, they found that child emotion and behavior problems were more directly related to caregiver strain than distress (Brannan & Heflinger, 2001).

As with caregiver distress, caregiver strain has been found to be high among parents of children with ASD, such that it could be equated to caring for a loved one with a serious brain injury (Cadman et al., 2012). Bradshaw et al. (2020) specifically assessed various predictors of caregiver strain among 323 children with confirmed ASD diagnoses. It was found that CPB was the biggest predictor of objective strain among these caregivers. This is hypothesized to be because problem behavior is disrupting family routines, interrupting personal time, and leading to family members missing work—all of which are aspects of objective strain.

Previous research has investigated the mediating role of caregiver strain in the relationship between CPB and parental distress levels. Specifically, Sales et al. (2004) found that maternal strain was a mediator between CPB and maternal depression, anxiety, and overall mental health. Further, there was a more direct relationship between internalizing symptoms and maternal distress, as opposed to an indirect relationship for child externalizing behaviors. This indicates that CPB likely affect maternal mental health through the caregiving strain that mothers

experience. However, this is the only study to date that has examined the mediating role of caregiver strain among caregivers of children with behavioral problems, particularly among those with ASD. Thus, the present study seeks to expand on this research by assessing caregiver strain as a mediator between CPB and caregiver distress in caregivers of children with ASD.

2.3 Resilience and Positive Cognitions

Despite the high levels of distress and strain compared to parents of typically developing children, many parents of children with ASD show resilience. Studies have found that positive experiences with parenting buffer against the negative effects of stressors experienced by caregivers of children with ASD. Thus, researchers have begun identifying caregiver coping strategies that can assist in reducing these distress levels (Benson, 2014; Smith et al., 2008; Weiss et al., 2012).

Several studies have assessed resilience among caregivers of children with ASD by looking at positive cognition. In a study of twenty-three pairs of mothers and fathers raising children with ASD, it was found that by assessing positive experiences with their children (e.g., “the child is a source of happiness and fulfillment”), mothers and fathers who reported more positive experiences, also reported lower stress levels (Kayfitz et al., 2010). Thus, it is possible that focusing on more positive aspects of a child, rather than limitations, is related to a decrease in parenting distress.

Many coping and resilience strategies also involve positive emotions and cognitions. For example, Wiess et al. (2012) found that, in caregivers of children with ASD, acceptance of difficult emotions and thoughts was a partial mediator in the relationship between child behavior

problems and mental health outcomes. In another study, Smith et al. (2008) found that in mothers of children with ASD, higher problem-focused coping (i.e., reframing a difficult event in a positive way) and lower emotion-focused coping (i.e., behavioral disengagement with stressor) were related to higher levels of well-being. Furthermore, positive cognitions have been found to mediate the relationship between caregiver depression and CPB (Bekhet, 2016). Caregivers may draw on positive elements of caregiving, or find benefit, to alleviate distress, even in the face of CPB.

2.3.1 Caregiver Benefit Finding

CBF is an emerging positive cognition that is defined as the positive impact that caregivers feel when caring for a child (Amtmann, Liljenquist, et al., 2020). CBF specifically refers to feelings that caregiving has added meaning to life, increased confidence, increased feelings of connectedness to others, etc. (Amtmann, Liljenquist, et al., 2020; Kim et al., 2007). Although only a limited number of studies have explored CBF among caregivers of children with ASD, results from studies of similar populations (i.e., chronic illness) show promising results. In families caring for cancer survivors, CBF was significantly positively correlated with positive psychological adjustment, and significantly negatively correlated with both psychological distress and perceived stress (Cassidy, 2013; Kim et al., 2007). In families caring for children with cerebral palsy, positive reinterpretation (i.e., meaning-making) was related to higher self-efficacy and lower rates of depression and stress (Cheshire et al., 2010).

Evidence of resilience has been seen in studies looking at CBF and related constructs, such as family connectedness, meaning-making, and strength building among caregivers of children with ASD. Bayat (2007) found that around 62% of families said they felt closer as a result of having a child with ASD, and around 39% of families felt that having a child with ASD

was an affirmation of strength. CBF has also been found to protect against the negative effects of increased stress in parents of children with ASD (Pakenham et al., 2004). Markoulakis et al. (2012) found that among female caregivers, while there were many costs to raising a child with ASD, benefits that were found led to positive recall of the caregiver experience, effectively outweighing the negatives.

In addition to decreased distress, CBF may also have additional positive effects for caregivers. Resilience can also be seen among caregivers rearing a child with ASD together, in terms of relationship satisfaction. Sim et al. (2019) found that among partners raising a child with ASD, those that displayed shared beliefs of acceptance, focusing on the positive, and meaning-making showed high relationship satisfaction, and overall resilience. Ekas et al. (2015) found that among sixty-seven couples caring for children with ASD, benefit finding predicted greater satisfaction with the relationship. This study was unique in that it assessed several positive cognitions, including optimism, coping strategies, and social support, in relation to relationship satisfaction, however benefit finding, and social support were the only factors that predicted both individual and partner satisfaction.

Lovell and Wetherell (2020) utilized a similar model as the one that is currently proposed. They assessed the moderating role of CBF in problem behavior and distress in caregivers of children with ASD. Problem behavior was positively, and CBF was negatively, related to psychological distress in caregivers, however no moderating effects were found. There are a couple of reasons why the current study is expected to find differing results, and thus expand upon this study. Firstly, the measure used to assess problem behavior in Lovell and Wetherell's (2020) study was methodologically limited. They utilized the strengths and difficulties questionnaire (SDQ; Goodman, 1997), which is a self-report measure that was

established for assessing psychopathology in typically developing children in a true or false format. Not only does the present study use a measure specifically created for neurodivergent children, but it also allows caregivers to expand upon the severity of the behavior. Another limitation of the SDQ is that it utilizes different batteries based on the age of the child, and thus relying on one measure would exclude certain age ranges. Secondly, Lovell and Wetherell possibly neglected to find any moderation effects, because CPB are not directly related to caregiver distress, but rather, the behavior is putting strain on the caregiver, which in turn is increasing distress levels. By adding caregiver strain in as a mediator in the relationship between CPB and caregiver distress, the current study looks at the moderating effects of CBF on the relationship between caregiver strain and psychological distress.

CHAPTER III

STATEMENT OF PURPOSE

There is a paucity of research investigating the role of CBF in caregivers' experience of parenting a child with ASD. As studies continue to find that these caregivers are experiencing higher levels of depression, anxiety, stress, and strain, it is essential the researchers find protective factors for these caregivers. Previous studies have lacked adequate measures and statistical designs to explore the components involved in caregiver distress resulting from CPB. It is imperative to understand the impact of CBF on the relationship between CPB, caregiver strain, and caregiver distress, in caregivers of children with ASD. In addition to better understanding the construct of CBF and caregiver strain in relation to CPB, the present study has implications for future development of CBF-based interventions for caregivers. This research is needed to fill a gap in the literature to determine the role of CBF in relation to caregiver strain and distress associated with caring for a child with increased CPB in conjunction with ASD.

3.1 Aims and Hypotheses

The purpose of this research is outlined through the following specific aims and hypotheses:

Specific Aim 1: To examine the relationship between CPB and caregiver distress, with caregiver strain as a mediator to this relationship, in children with ASD and their caregivers.

Rationale: Previous research has found that increased CPB in children with ASD is related to significantly increased caregiver distress and strain. The relationship between these three constructs has yet to be established.

Hypothesis 1 The relationship between CPB and caregiver distress will be mediated by caregiver strain.

Specific Aim 2: To assess the relationship between caregiver strain and caregiver distress, with this association moderated by CBF, in caregivers of children with ASD.

Rationale: Previous research has looked at positive cognition, specifically CBF, as a protective factor for caregiver distress. There is yet to be a study assessing the effect CBF has on caregiver distress.

Hypothesis 2 The relationship between caregiver strain and caregiver distress will be moderated by CBF.

Specific Aim 3: Assess a moderated mediation of the relationship between CPB and caregiver distress (See Figure 1).

Rationale: Previous research has yet to assess the mediating role of caregiver strain in the relationship between CPB and caregiver distress, nor the moderating role of CBF in this mediation. It is expected that these factors are all interrelated.

Hypothesis 3 There will be a moderated mediation of the relationship between CPB and caregiver distress, with objective caregiver strain mediating this relationship, and CBF moderating the relationship between caregiver strain and distress.

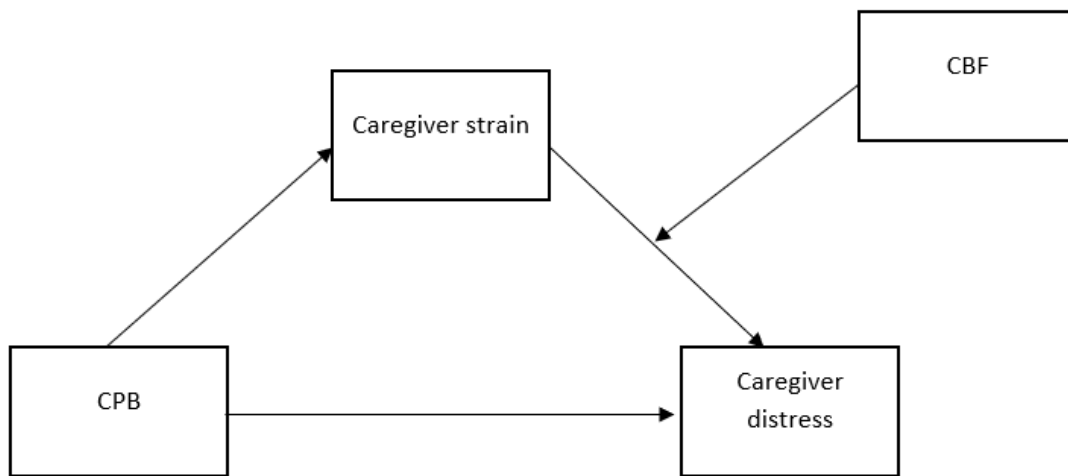


Figure 1. Moderated Mediation of CPB, Caregiver Strain, CBF, and Caregiver Distress

CHAPTER IV

METHODOLOGY

4.1 Design

A quantitative, cross-sectional design was utilized in this study. Archival data from a previous study, in which participants completed survey questions based on pre-existing diagnoses which distinguished caregivers based on sample group differences, was used to assess the hypotheses. The current study used a sample of female caregivers of children with ASD.

4.2 Participants

Caregivers of children with ASD were recruited online through the Interactive Autism Network (IAN), an online network through Kennedy Krieger Institute, as part of a larger study. To enroll in the IAN program, caregivers must give consent and verify having legal guardianship of a child under 18 years of age with one of the following diagnoses given by a licensed professional: Autism or Autistic Disorder, Asperger Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorders, and Autism Spectrum Disorder ("Taking Part in IAN Research", 2007). In order to participate in IAN research, the caregiver must complete specific protocol, which includes completion of the Social Responsiveness Scale, Social Communication Questionnaire (SCQ), Treatment List, a Child with ASD Questionnaire asking specifics about diagnostics ("IAN research questions", 2007). The IAN registry has been clinically validated as caregiver reported diagnoses are verified by review of provided medical

records (Lee et al., 2010). For these reasons, participants recruited through IAN can be considered as valid responders with verified diagnostic qualifications.

The inclusion criteria for this group of caregivers included 1) being the primary caregiver of a child between the ages of 2 and 12 years old; 2) being a caregiver ranging in age between 20 and 60 years old; 3) having a child that has been formally diagnosed with ASD; 4) being a caregiver that is a United States citizen; and 5) having English as a primary language. The survey was sent to a total of 1,820 families through the IAN, and 570 individuals engaged with the survey. Originally, participants were automatically excluded if their child had a co-occurring intellectual disability, but due to the exclusion of high numbers of participants, the survey was altered to let children with co-morbid diagnoses to indicate additional conditions and continue with the rest of the survey. Participants were excluded if study criteria were not met (e.g., no ASD diagnosis, caregiver age, child age) and if child had other severe illnesses (e.g., Cerebral Palsy, Stroke, Rett's Syndrome) to better isolate factors related to caring for a child with ASD. In order to control for the effects of gender on caregiver strain and distress, and because they made up 91% of the sample, only female caregivers were included in this study. After controlling for inclusion criteria and removing male caregiver data, the final sample included 259 female caregivers of children with ASD.

4.3 Measures

4.3.1 Demographic Information

Demographic information gathered included general information on individual and family characteristics such as caregiver and child age, ethnicity, and number of adult members in

the household. Questions specifically directed to the caregiver included highest education level achieved, occupation, and any birthing complications. Caregivers were asked if the child had any psychiatric or major medical diagnoses.

4.3.2 Child and Parental Efficacy Scale

The Child and Parent Efficacy Scale- Developmental Disability (CAPES-DD; Mazzucchelli et al., 2016) was given to measure CPB. This is a 24-item measure that was developed from the original child and parent efficacy scale to examine a variety of strengths and difficulties across emotional and behavioral domains in children from ages 2 to 16 with developmental disabilities. Caregivers are asked to rate the applicability of the statement from 0 (i.e., “not true of my child at all”) to 3 (i.e., “very much true of my child”), over the past 4 weeks. These items make up 3 subscales: behavioral problems, emotional problems, and prosocial behavior. For the purpose of this study, only scores from the 10-item behavioral problem subscale was used. The sum of these items ranged from 0 to 30. Good convergent and predictive validity have been found for the behavioral problem subscale of this measure, as well as good internal consistency, as shown by a Cronbach’s alpha of $\alpha = 0.89$ when tested with caregivers of children with developmental disabilities ($N = 636$) in two studies (Emsler, et al., 2016).

4.3.3 Depression Anxiety Stress Scale

The Depression Anxiety Stress Scale-21 (DASS-21; Lovibond & Lovibond, 1995; Antony et al., 1998) is a 21-item self-report measure made up of three scales, 7 items each, examining negative emotionality related to stress, anxiety, and depression. These items were obtained from the full version of the 42-item DASS (Lovibond & Lovibond, 1995). Depression symptomology is evaluated through questions of hopelessness, perception of self, value of life,

and anhedonia. Anxiety symptomology is assessed with levels of physiological response along with personal feelings of nervousness, worry, and panic. Stress is assessed through levels of reactivity, agitation, and inability to relax. Each item requires the respondent to evaluate feelings over the past week on a scale from 0 (“it did not apply to me at all”) to 4 (“applied very much, or most of the time”) with total raw scores ranging from 0 to 84 (Lovibond & Lovibond, 1995). The raw scores from each subscale must be totaled and then multiplied by two, in order to evaluate clinical significance compared to the full form of the DASS. According to full form DASS scoring, scores ranging 0 to 20 indicate “normal” to “moderate” depressive symptomology, 21 to 27 indicates “severe” depressive symptomology, and scores of 28 or more indicate “extremely severe” depressive symptomology (Lovibond & Lovibond, 1995). Lovibond and Lovibond (1995) determined scores ranging from 0 to 14 indicate “normal” to “moderate anxiety symptomology, 15 to 19 indicate “severe” symptomology, and a score of 20 or higher indicates “extremely severe” anxiety symptomology. Scores ranging from 0 to 25 indicate “normal” to “moderate” stress, with scores falling in the 26 to 33 range indicating “severe” stress, and scores 34 or higher indicating “extremely severe” stress (Lovibond & Lovibond, 1995). For the purpose of this study, a total DASS score was used to represent caregiver distress. Other studies made up of large sample sizes have shown strong psychometric properties of the DASS including highly stable factor structure, convergent validity ($r = 0.45-0.66$), reliability ($\alpha = 0.89-0.96$), directionality prediction, and clinical accuracy (Antony, et al., 1998; Brown, et al., 1997).

4.3.4 Caregiver Strain Short Form

The Caregiver Strain Questionnaire-Short Form (CGSQ-SF; Bickman et al., 2007) is a 10-item self-report measure that is completed by adult caregivers to evaluate the effect of

providing care for a child with particularly increased needs (i.e., developmental disability). Questions include six items of objective, or externally observable, effects of strain, and four items of subjective, or internalized feelings of strain felt by the adult caregiver based on the last 6 months. For this study, only the objective items was used to assess strain. Each statement assessing the event creating strain is measured on a scale ranging from 1 (“not at all”) to 5 (“very much”). A clinical cutoff score of 3.0 was generated for objective strain (Bickman et al., 2007). Equal to or greater scores than the cutoff indicate increased levels of caregiver strain. Acceptable to good internal consistency has been found for the objective subscale ($\alpha=0.76-0.88$) across studies (Bickman et al., 2007; Jacob et al., 2017).

4.3.5 Caregiver Benefit Scale

The Caregiver Benefit Scale (CBS; Amtmann, Liljenquist, et al., 2020) is a 13-item self-report completed by the caregiver that evaluates the amount of positivity they experience while being a caregiver. Items assessed these positive aspects in various ways, including how much the caregiver appreciates life, find new strengths in themselves, feels caregiving has made them a better person, etc. The caregiver is asked to choose the response that best described how they usually felt about caregiving on these items. The responses were rated on a five-point scale from 1 (“Not at all”) to 5 (“Very much”). Following scoring guidelines, the item responses from items 1-7 and 12 were totaled, and then converted to an IRT based t-score to represent a benefit finding score. Items 8-11 were excluded because they were not included in the updated version of the CBS (Amtmann, Jensen, et al., 2020). Item 13 was excluded because it specifically asked about partner closeness, which excluded single caregivers. This measure has been found to have good

construct validity, when compared to known clinical groups of children with Down's Syndrome, and good test-retest and IRT reliability ($ICC > 0.92$) (Amtmann, Liljenquist, et al., 2020).

4.4 Data Analysis

Statistical analyses were conducted through SPSS. Preliminary analyses were conducted to assess for significant Pearson's correlations between the main study variables, using a significance value of $p < .05$, in order to establish basic relationships. Individual ANOVAs assessed whether there were statistically significant differences in caregiver strain and caregiver distress based on marital status, ethnicity, and caregiver education. A linear regression model assessed whether child age was significantly related to caregiver strain and caregiver distress. Data was analyzed for normality, skewness/kurtosis and for the presence of any unexpected outliers. The measure for caregiver distress, DASS-21 total score, was significantly positively skewed, and was transformed using a square-root function in order to achieve normality.

The first hypothesis that was tested is that the relationship between child behavioral problems predicting caregiver distress, and mediated by caregiver strain using model 4 of the PROCESS macro for SPSS (Hayes, 2018) a nonparametric bootstrapped model with 5,000 re-samples. Furthermore, the indirect relationship between the predictor, CPB, and outcome, caregiver distress, were assessed for significance by looking at the bootstrapped confidence intervals. Finally, the R-squared value was interpreted in order to assess the percentage of variance in the outcome that can be explained by the mediation model.

Secondly, it is hypothesized that the relationship between caregiver strain and caregiver distress were moderated by CBF. A moderation analysis was run using model 1 of the PROCESS

macro for SPSS (Hayes, 2018), to explore the moderation, with caregiver strain as the predictor variable, caregiver distress as the outcome variable, and CBF as the moderator variable. In the macro, simple slopes were interpreted by setting them at ± 1 standard deviation of the mean of the moderator. In order for the moderation to be significant, the p-value of the interaction must be $p < .05$.

Finally, Hayes' process procedure for a moderated mediation model was used to assess the change between CPB and caregiver distress, with objective caregiver strain mediating this relationship, and CBF moderating the relationship between caregiver strain and distress. A moderated mediation analysis using model 14 of the PROCESS macro for SPSS (Hayes, 2018), was done to assess the moderated mediation with CPB as the predictor variable, caregiver distress as the outcome variable, caregiver strain as the mediator variable between CPB and caregiver distress, and CBF as a moderator on the relationship between caregiver strain and distress. For this analysis, the confidence interval was set at 95%. In order to assess the indirect effects of the predictor (CPB) on the outcome (distress), 5,000 bootstrap resamples were used. For moderation, simple slopes were interpreted by setting them at ± 1 standard deviation of the mean of the moderator. In order for the mediation to be determined to be significant, the confidence interval must not include 0. Furthermore, the indirect relationship between the predictor and outcome were assessed for significance by looking at the bootstrapped confidence intervals, and seeing if they include 0. Finally, the R-squared value was interpreted in order to assess the percentage of variance in the outcome that can be explained by the mediation model. In order for the moderation to be significant, the p-value of the interaction must be $p < .05$.

The moderated mediation model tests the relationships between X, Moderator, and the interactions between Y, moderator, and mediator. The results were shown using unstandardized coefficients and bias-corrected 95% confidence intervals.

CHAPTER V

RESULTS

5.1 Participant Characteristics

Participating female caregivers had a mean age of 40.27 years ($SD = 5.98$). The majority of caregivers were married (68.6%) and had a Bachelor's degree (35.9%). Caregivers identified as Caucasian (75.6%), African-American (7.4%), Hispanic (10.9%), Asian (3.1%), Multi-Racial (1.9%), and another ethnicity (2.3%). Participating children included 259 children with 205 identified as male (79.2%) with a mean age of 8.78 ($SD = 2.55$). The children ranged in age from 2-12 years old.

5.2 Preliminary Analyses

Caregiver distress was unrelated to any demographic factors (all $ps > .10$), and caregiver strain was unrelated to caregiver ethnicity, education level, and marital status (all $ps > .09$). Caregiver strain was significantly negatively related to child age ($r = -.169, p = .007$). CPB was significantly positively related to caregiver strain ($r = .506, p < .001$) and caregiver distress ($r = .312, p < .001$), but unrelated to CBF ($r = -.122, p = .05$). CBF was negatively related to caregiver distress ($r = -.216, p < .001$) and caregiver strain ($r = -.286, p < .001$). Caregiver distress was positively related to caregiver strain ($r = .422, p < .001$). Table 1 displays relationships between study variables.

Table 1 Means, Standard Deviations, and Correlations for Study Variables

	1	2	3	4	Mean	SD	Range
1. CPB	-				13.5	6.1	1-30
2. Distress	.312**	-			34.7	25.3	0-124
3. Strain	.506**	.422**	-		3.1	0.9	1.17-5
4. CBF	-.122	-.216**	-.286**	-	50.5	11.5	20.2-68.8

CPB child problem behaviors

CBF caregiver benefit finding

** $p < 0.001$

5.3 Hypothesis 1: Mediation Testing

Hypothesis 1, objective caregiver strain would mediate the relationship between CPB and caregiver distress, was tested through the Hayes PROCESS Macro as described above. Child age was entered as a covariate in order to control for its effects on caregiver strain, as preliminary analyses indicated a significant negative relationship between strain and child age. In the first step of the mediation analysis, the regression of CPB on caregiver strain was significant, $b = .073$, $t(236) = 9.072$, $p < .001$. According to the R^2 value, CPB explained 28% of the variance in caregiver objective strain, and the positive b value showed that as CPB increases, caregiver strain increases as well.

The next step of the mediation process showed that the mediator (caregiver strain), controlling for child age, was significantly related to caregiver distress, $b = 0.05$, $t(235) = 2.03$, $p = 0.04$. The total effect of CPB on caregiver distress within the mediation was significant ($b = 0.12$, $p < .001$), and the direct effect of CPB on caregiver distress was significant, $b = 0.9$, $t = 5.267$, $p < .001$. The indirect effect of CPB on caregiver distress through caregiver strain was

significant, $b = 0.07$, $SE = .015$, $95\% \text{ CI} = [0.037, 0.097]$. The R^2 value shows that the model explains 20.4% of the variance in caregiver distress. In sum, Hypothesis 1 was fully supported.

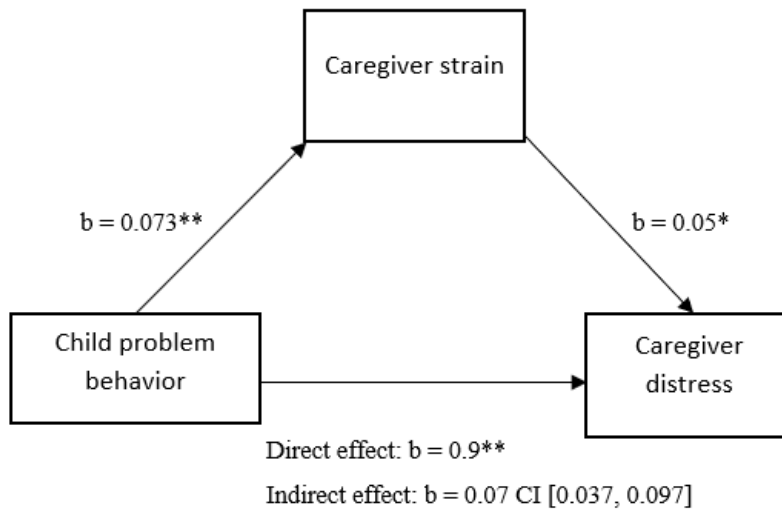


Figure 2. Mediation of CPB, Caregiver Strain, and Caregiver Distress.

* $p < .05$, ** $p < .001$

5.4 Hypothesis 2: Moderation Testing

In order to test Hypothesis 2, that the relationship between caregiver strain and caregiver distress will be moderated by CBF, a moderation analysis was tested through the Hayes PROCESS Macro. Child age was entered as a covariate in order to control for its effects on caregiver strain. For caregiver distress, the regression model, which included caregiver strain, CBF, and the interaction between the variables, accounted for 20.9% of the variability ($F(4, 240) = 15.81, p < .001$), with CBF emerging as a unique predictor ($b = -0.078, p = .039$) but not caregiver strain ($b = 0.095, p = .87$), or the interaction between the two variables. Thus, benefit

finding was not found to be a significant moderator $b = .018$, 95% CI $[-0.0037, 0.0395]$, $t = 1.64$, $p = 0.10$. Therefore, Hypothesis 2 was not supported.

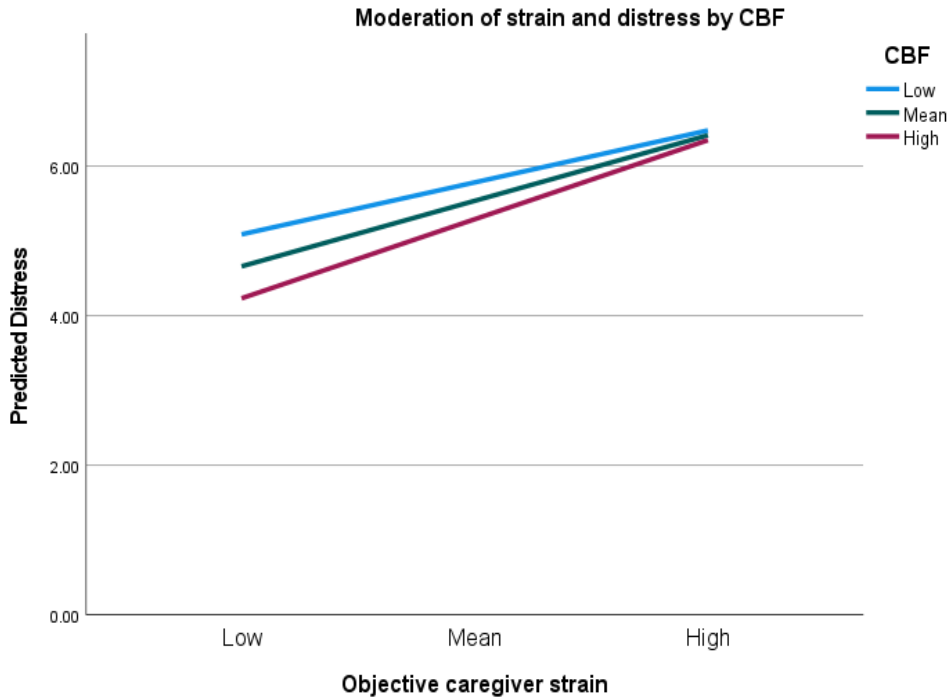


Figure 3. Moderation of Caregiver Strain and Caregiver Distress by CBF.

5.5 Hypothesis 3: Moderated Mediation Testing

Finally, Hypothesis 3, a moderated mediation analysis, was tested through the Hayes PROCESS Macro. Child age was again entered as a covariate in order to control for its effects on caregiver strain. CPB ($b = 0.054$, $p = .026$), caregiver strain ($b = 0.779$, $p < .001$), and CBF ($b = -0.024$, $p = .044$) all had significant direct relationships with caregiver distress within the moderated mediation model. The direct effect of CPB on caregiver distress was significant ($b = 0.054$, $p = .026$), and the effect of CPB on caregiver strain remained significant as well (b

= .073, $t = 9.072$, $p < .001$), and thus, caregiver strain was a significant mediator in the model.

However, CBF was not a significant moderator within the model ($b = 0.019$, $p = .08$). According to the R^2 value, the model accounted for 22.5% of the variation in caregiver distress.

The index of the moderated mediation model was found not to be significant ($b = 0.001$, 95% CI $[-0.0003, 0.0033]$). The conditional indirect effects of CPB on caregiver distress through caregiver strain were significant for all values of CBF ($-1SD$, mean, $+1SD$), however there were no significant differences between the values. In sum, Hypothesis 3 was not fully supported.

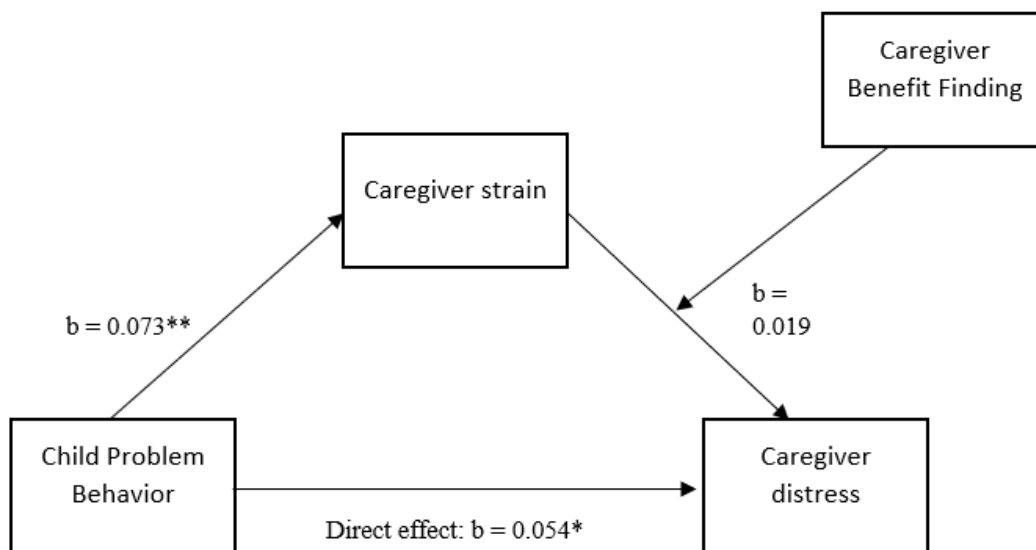


Figure 4. Moderated Mediation of CPB, Caregiver Strain, CBF, and Caregiver Distress.

* $p < .05$, ** $p < .001$

CHAPTER VI

DISCUSSION

The current study aimed to expand upon the caregiver strain literature by examining the mediating effects of objective caregiver strain on the relationship between child problem behaviors (CPB) and caregiver psychological distress, utilizing a sample of female caregivers of children with ASD. Furthermore, the present study sought to assess the potential moderating effects of caregiver benefit finding (CBF) on caregiver mental health outcomes. Finally, this study assessed for both mediation and moderation in a combined moderated mediation model in order to further parse apart the roles of each unique variable.

The preliminary analyses revealed that caregiver distress was unrelated to any demographic factors, and caregiver strain was unrelated to all demographic factors except for child age. Thus, child age was entered into the subsequent analyses as a control variable. It is notable that objective caregiver strain was negatively related to child age, suggesting that caregivers of younger children are likely to experience higher levels of objective caregiver strain. There are a couple possible explanations for this pattern. It is more likely that caregivers of younger children have more recently received an ASD diagnosis, and are still adjusting to the demands of caring for a child with ASD. It is also likely that caregivers of younger children are likely to be newer to treatment, and thus experiencing more intense symptoms with limited coping strategies at their disposal. It is also possible that this relation appears because younger children may be more likely to not attend out of the home care.

6.1 Specific Aim 1: Caregiver Strain as a Mediator

The first aim of the study was to assess the role of caregiver strain in the relationship between CPB and caregiver distress. This hypothesis was supported, objective caregiver strain mediated the relationship between CPB and caregiver psychological distress. This finding is congruent with previous research assessing caregiver strain as a mediator. Specifically, the results uphold findings from Sales et al. (2004), in which strain was found to be a mediator between CPB and maternal mental health. Furthermore, the present findings corroborate the idea that CPB likely affect maternal mental health through the objective caregiving strain that mothers experience, particularly with children with ASD (Sales et al., 2004).

The confirmation of objective strain as a significant mediator in the relationship between CPB and caregiver distress supports the prediction that problem behaviors are not directly related to caregiver distress, but rather, the behavior is putting strain on the caregiver, which in turn is increasing distress levels. These results also further support the idea that caregiver strain is a separate but related construct to caregiver distress, both of which are affected by CPB (Brannan & Heflinger, 2001).

Female caregivers of children with ASD are found to experience higher levels of distress when caring for a child with increased CPB (Goodman et al., 2011; Yorke et al., 2018). The significant direct predictive relationship between CPB and caregiver distress found in this study further supports this finding. Previous literature assessing CPB as a predictor for objective caregiver strain (Brannan & Heflinger, 2001; Sales et al., 2004) also support the finding of the significant predictive relationship between caregiver strain and CPB.

6.2 Specific Aim 2: Caregiver Benefit Finding as a Moderator

The second aim of this study was to assess the relationship between caregiver strain and caregiver distress, with the relationship being moderated by CBF. Although there were significant relationships between the main study variables, this hypothesis was not supported. Given previous research that failed to identify CBF as a moderator (Lovell & Wetherell, 2020), the current finding is not surprising. The present findings support the idea that while CBF is a significant factor in a caregiver's global mental health, it is not a moderator between strain and psychological distress, and thus may not be a strong protective factor.

It is possible that the second hypothesis was not supported, because the relation and direction in which CBF is related to the measured variables was negative. For instance, CBF was significantly negatively correlated with both caregiver strain and psychological distress. Therefore, caregiver strain and psychological distress may directly affect CBF. Similarly, if caregivers are experiencing feelings of being overwhelmed, they may not have the cognitive and emotional resources to find benefit. The role of CBF in a caregiver's mental health remains substantial, as evidenced by the significant predictive relationship between CBF and caregiver distress. This relation may be of importance to research in the future, as this predictive relationship does support the idea of CBF being somewhat of a protective factor against caregiver psychological distress. Although the exact role of CBF in maternal mental health has yet to be explored, these results point researchers in a promising direction.

6.3 Specific Aim 3: Moderated Mediation

The third and final aim of this study was to assess a moderated mediation of the relationship between CPB and caregiver distress, with caregiver strain mediating this relationship, and CBF moderating the relationship between caregiver strain and caregiver distress. As with the moderation results, although there were significant relationships within this model, this hypothesis was not supported. While the mediation remained significant, the moderation was not, and thus the model failed.

CBF is not a moderator between strain and psychological distress, and Lovell and Wetherell's (2020) findings further corroborate these findings by showing that CBF is not a moderator between CPB and distress. It is possible that situational factors, such as specific objective strains, are where the moderation is failing. It is also important to note that in both the current thesis and in Lovell and Wetherell's (2020) study, CBF was unrelated to CPB, which could also be an explanation of why these models fail. Consistent with previous research, the current study supports that CBF plays a significant role in caregiver's global mental health, and thus it is not a construct to completely discount as insignificant.

Despite the hypothesized role of CBF as a moderator not being supported, this study does give evidence that despite high levels of distress and strain, many caregivers show resilience. Previous research supports this finding, and allows us to further assess the role of positive cognitions in a caregiver's global mental health. The current study utilized a measure that assessed several aspects of CBF (i.e., appreciation for life, strengths, meaning in life). Caregivers of children with ASD often derive positive meaning-making from their child having ASD (Myers et al., 2009), which has been found to help families develop resiliency to psychological distress (Bayat, 2007; Larson, 2010).

Previous studies support the findings that meaning-making contributes to resiliency in caregivers of children with ASD. Caregivers of children with ASD have been found to frequently discuss meaning-making in a support group (Huws et al., 2001). Further, Pakenham et al. (2004) found that parents of children with ASD talked about feelings of change in relation to their priorities, growth in faith/spirituality, and growth in self-control and meaning-making, which all protected against the negative effects of increased stress. Although parents are often experiencing more adversity in caring for a child with increased needs, finding benefit in being a caregiver of a child with a disability can be a protective factor for parent psychological distress.

6.4 Limitations

One notable strength of the present study is that the recruitment of caregivers of children with ASD was done through the Interactive Autism Network (IAN). This network utilizes protocols that require a significant amount of information to be gathered in order to participate in the resource network, allowing each child's diagnosis to be verifiable. Accurate diagnoses further support the validity and quality of responses in the current study for caregivers of children with ASD. However, the IAN is a convenience sample from an online recruitment organization; thus, the samples were limited to caregivers with internet access and limited in diversity. Due to the nature of cross-sectional designs, causation cannot be inferred. It is also important to note that the demographics of the sample are likely not generalizable to the general population. The sample included female caregivers that were a majority white, married, and educated. It is also notable that this study only contained female caregivers, as most literature also only looks at female caregivers, and thus additional research using male caregivers would be

needed to generalize the findings to paternal mental health effects. In addition, ASD symptom severity was not assessed, thus the effects of this variable on caregiver mental health within this sample cannot be determined. Finally, it is notable that the Caregiver Benefit Scale (CBS; Amtmann, Liljenquist, et al., 2020) is a fairly new measure of caregiver benefit finding, which is also a fairly new area of study. Thus, although there has been a study assessing the validity of this measure, more research is needed to represent this construct more accurately.

6.5 Future Directions

Based on current findings from the present study, future research should continue to focus on caregiver strain and the role it plays in the overall mental health of the caregiver of a child with ASD in order to develop interventions to relieve stress, anxiety, and depression. Given that objective caregiver strain was a mediator between problem behavior and psychological distress, it is important for interventionists to assess for factors contributing to high levels of strain (i.e., financial burden, daily routine disruption, leaving work for children). Thus, further research would be needed to assess for strain within clinical settings. Further research could also assess subjective strain, as this variable was not explored in this study.

It is important to fully explore positive cognition coping strategies, including CBF, because it allows researchers to shift away from a deficit model of parenting children with ASD to a growth perspective. Although the current findings did not support CBF as a moderator, it was still found to be a significant part of the mental health of a caregiver for a child with ASD. Exploring ways in which parents can lower distress levels may not only benefits the parent, but the child they care for as well. Thus, more research to further understand the role of CBF and

other positive cognitions is essential for lessening the suffering of those within the ASD community, and their loved ones.

The results of the present thesis indicate that CBF and objective caregiver strain are both important variables in the global mental health of female caregivers of children with ASD, specifically that caregiver strain is a mediator between CPB and psychological distress in caregivers. Results from the current study add to the caregiving literature and further address the positive role that benefit finding plays in caregiver feelings of stress, anxiety, and depression. By studying perceived levels of benefit-finding and objective strain among caregivers at risk for increased stress, anxiety, or depression, researchers and clinicians can increase their awareness as to the burden placed on caregivers of children with ASD and the impact on their global mental health. Researchers and clinicians should continue to focus on improving factors such as meaning-making, finding strengths in themselves, increase self-confidence, and increase feelings of connectedness to others. Development of prevention strategies, positive cognition (i.e., benefit finding) interventions, and treatments for caregivers could be better informed with the basis of this research and greater understanding of how the constructs interact with each other. In sum, this thesis highlights the need for the attention to be placed on the caregiver, in addition to the child, to maintain and even improve mental health outcomes for the family as a whole.

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