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The Relations Between Adherence to Behavioral Treatments and Parent Stress in Families of Children With ASD

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THE RELATIONS BETWEEN ADHERENCE TO BEHAVIORAL TREATMENTS AND
PARENT STRESS IN FAMILIES OF CHILDREN WITH ASD

by

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DEDICATION

This project is dedicated to the strong, courageous, brave parents of children with Autism Spectrum Disorder that I've worked with over the past five years. The way that you've demonstrated remarkable persistence in the midst of obstacles and unending love for your children truly amazes me. Light it up blue!

ACKNOWLEDGEMENTS

I could not have completed this work without the mentorship of Dr. Rob Hock, Dr. Stacy-Ann January, and Dr. Jane Roberts. I would like to acknowledge Dr. Rob Hock, who adopted me into his lab when I was looking for a research home and allowed me to use the data for this project. Dr. Stacy-Ann January helped me with conceptualizing my ideas and thoroughly checking my work for grammar and stylistic compliance. Dr. Jane Roberts supported my work and encouraged me to see this project through completion.

ABSTRACT

Recent studies suggest that parent involvement with behavior treatment for associated challenging behaviors (ACBs) may reduce parent stress in families with autism spectrum disorder (ASD). However, it is not known whether high treatment adherence to protocols is associated with reduced parent stress, or which factors that may moderate this relation. The current study examined the relation between parents' adherence to behavioral treatments and parent stress, and whether parents' perceptions toward treatment moderate this association. Participants were 190 mothers, fathers, or caregivers of a child with ASD. A bivariate correlation matrix examined associations between each variable, and 3 separate linear regression models regressed parent stress on treatment adherence, perceptions of treatment, and the interaction of the two. Treatment adherence had a significant negative relation with parent stress. Treatment burden, but neither treatment relevance nor treatment effectiveness, emerged as a moderator. These findings have implications for clinicians and treatment providers who are well positioned to monitor and address parent attitudes toward treatment.

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CHAPTER 1: INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disability affecting 1 in 59 people across the United States (CDC, 2018). The disorder is characterized by deficits in social functioning and communication, as well as the presence of restrictive behaviors and interests. Extant literature has considered the impact of the presence of ASD and concluded that family members, namely parents and caregivers, are at risk for negative wellbeing and adverse health outcomes, including chronic stress, depression, and anxiety (Ekas & Whitman, 2010; Hayes & Watson, 2013; Tint & Weiss, 2016). It is widely accepted that there are bidirectional influences between the child with ASD's wellbeing and that of their family members (Karst & Van Hecke, 2012). Furthermore, there has been an increased focus on including parents as deliverers of ASD treatment; however, few studies have adequately examined the impact of treatment engagement on parent stress (Oono, Honey, & McConachie, 2013). As a result, there is a call for more family-centered approaches to studying the effects of ASD to include both the child and family (Cridland, Jones, Magee, & Caputi, 2014; Tint & Weiss, 2016).

Family systems theory offers a lens with which to conceptualize the interrelated processes between family members when ASD is present. The theory posits that individual family members function as subsystems (Minuchin, 1985). These subsystems are independent units existing in an open system; moreover, these subsystems have open boundaries which allow interactions with each other, resulting in changes in the system.

Thus, family members exert reciprocal influences on one another, and the characteristics of a child with ASD create unique experiences within the family system (Head & Abbeduto, 2007). For example, ASD is associated with a greater number of challenging behavior problems than any other development disability (Herring, Gray, Taffe, Tonge, Sweeny, & Einfeld, 2006). Moreover, parents of children with ASD consistently present with elevated stress, pessimism, and depression (Head & Abbeduto, 2007). These findings provide context for understanding family dynamics when ASD is present and are described below.

Parent stress

It is well documented that parents of children with ASD experience significant levels of stress, at even higher rates than parents of children who have other developmental disabilities or are typically developing (Hayes & Watson, 2013; Osborne & Reed, 2009; Van Steijn, Oerlemans, Van Aken, Buitelaar, & Rommelse, 2014). The long-term effects of parent stress are troubling, and they include poorer wellbeing and mental health concerns (Ekas & Whitman, 2010). Unfortunately, parents with impaired psychological wellbeing and increased stress are less likely to participate in treatment for their child (Kazdin & Mazurick, 1994; Kazdin & Wassell, 2000). Additionally, parent stress may reduce or mask the positive effects of ASD intervention (Osborne, McHugh, Saunders, & Reed, 2008b). These findings are cause for concern when considering treatment options for ASD. It may be as important to attend to parent wellbeing as it is to consider the needs of the child with the disability, lest the treatment be hampered. From a family systems perspective, the unique challenges of the disability and its effect on other family members should be factored into treatment decisions (Head & Abbeduto, 2007).

Child characteristics partially explain elevated levels of parent stress in families with ASD. As stated above, ASD is associated with a greater number of behavioral issues than any other developmental disability (Herring, Gray, Taffe, et al., 2006). Associated challenging behaviors (ACBs) are common for children with ASD and include both externalizing behavior (e.g., aggression, self-injurious behavior, etc.) and internalizing problems (e.g., anxiety; Matson & Nebel-Schwalm, 2007). The significant association between parent stress and ACBs is well established, with researchers estimating correlations between .28 and .40 for externalizing behaviors (i.e., self-injurious behavior and conduct problems, respectively) and between .17 and .41 for internalizing behavior (i.e., insecure/anxious and adaptive/social, respectively; Lecavalier, Leone, & Wiltz, 2006). Stress and ACBs appear to have bidirectional effects on each other over time, such that an increase in parent stress leads to more behavior problems, and vice versa (Zaidman-Zait et al., 2014). Potential mechanisms for this relation are the transactions occurring between parents and children, in which highly stressed parents exhibit more negative parenting behaviors, including reduced limit setting (Hastings, 2009; Neece, Green, & Baker, 2012; Osborne, McHugh, Saunders, & Reed, 2008a). These behaviors, in turn, lead to increased child behavior problems, which then create additional stress for the parent. The idea of transactions, or two or more parties reacting and adjusting to one another, aligns with family systems theory, in that members of each subsystem are reciprocally imparting influence on one another.

Behavior Treatment and Parent Involvement

Given the substantial correlation between parent stress and ACBs, it is unsurprising that behavior treatment is among the most common treatments for

individuals with ASD (Green et al., 2006; Myers & Johnson, 2007). Behavior treatment, commonly delivered through applied behavior analysis therapy (ABA), utilizes strategies based on the principles of operant conditioning. A key component of ABA therapy is modifying aspects of the environment and altering the contingencies for reinforcement or a consequence, which shape socially significant behavior. The field of ABA therapy is well established, and an abundance of studies from the past six decades have supported the use of ABA therapy to treat behavior problems in individuals with ASD (Foxy, 2008). Long-term involvement with ABA therapy has medium to large effects on intellectual functioning, adaptive skills, and language development in individuals with autism (Virues-Ortega, 2010). Strict adherence to the treatment protocol aids in treatment gains (Klintwall, Gillberg, Bölte, & Fernell, 2012). Although there is variability among ABA models, some unifying features include intensive dosage (i.e., 30-40 hours per week), individual treatment plans, and the training of parents as co-therapists (Virues-Ortega, 2010).

Parent involvement in behavior treatment, (i.e., parents receiving direct training on ABA techniques and implementing them with fidelity), is considered a key element to the success of behavior therapy (Karst & Van Heck, 2013). In a review of the literature, Karst and Van Heck (2013) found that parent involvement in treatment is viewed as essential, as parents are the most prominent adult in the child's day-to-day life. Additionally, involvement can improve parent wellbeing, as parents learn strategies for managing behavior and grow in their confidence in caring for a child with ASD. Parent training of techniques has been shown to lead to better long-term behavior change than treatment without parent involvement (Vismara, Colombi, & Rogers, 2009). Furthermore,

there has been an increased focus on including parents as early interventionists, which has demonstrated success in improving their children's outcomes as parents develop strategies for managing behavior (Oono et al., 2013).

Knowledge about the effect of parent involvement with ASD treatment on parent stress levels is limited (Oono et al., 2013). Moreover, there is evidence that parent involvement in intervention can increase parent stress. For example, Rivard et al. (2017) found that their parent coaching program effectively reduced behavior problems in children with ASD, yet parents reported significantly more stress after 12 months of treatment. Although parents reported that they were highly satisfied with the intervention, the authors suggested that they experienced increased stress because they perceived that the coaching program was insufficient for fully treating their child's needs. However, parents' overall engagement with the intervention was not measured, and it is unclear whether variance in levels of involvement was related to stress.

Parent involvement in treatment as defined by their adherence to treatment may partially explain variance in parent stress. Treatment adherence refers to the extent to which a patient implements a prescribed treatment protocol, and it is necessary for desired therapeutic outcomes (Meichenbaum & Turk, 1987). Behavior therapy for ASD often employs caregivers to consistently implement an individualized protocol to manage their child's problem behavior (Kashinath et al., 2006). Interestingly, parent adherence to ASD treatment has been identified as the lowest in intensive behavior treatment, compared with speech-language therapy, dietary interventions, and occupational therapy (Shepherd, Landon, Goedeke, Ty, & Csako, 2018). Moreover, Moore and Symons (2009) found that adherence to behavior therapy was significantly less than medical treatment

recommendations. Nevertheless, there is evidence that behavior therapy in general is associated with reduced parent stress (Hastings & Johnson, 2001), to a greater degree than the aforementioned therapies (Shepherd, Landon, Goedeke, Ty, & Csako, 2018). Thus, parents may have the most difficulty adhering to the very treatments that may be associated with the greatest stress reduction, but this phenomenon is not well understood.

Perceptions of Treatment

Perceptions of treatment influence parents' adherence to their child's treatment. The Barriers-to-Treatment Model (Kazdin, Holland, Crowley, & Breton, 1997) suggests that there are features of treatment outside of practical elements (e.g., transportation to and from treatment centers) that affect families' participation in therapy. Perceived barriers to treatment include the degree to which parents find treatment to be helpful, demanding, and relevant, as well as the perceived alliance with treatment providers and other procedural obstacles (e.g., behavior problems with siblings that interfered with treatment). In families receiving psychiatric treatment for their children, Kazdin, et al. (1997) found that parents who reported a high number of barriers were more likely to prematurely drop out of treatment, attend fewer sessions, and have higher numbers of cancellations and no-shows. Parent engagement with therapy is also sensitive to cognitions about the treatment, specifically the expectation that treatment is helpful (Morrisey-Kane & Prinz, 1999). The perceptions of treatment burden, treatment relevance, and treatment effectiveness are all implicated with treatment adherence, and they may partially explain the variance in parent stress.

Treatment burden. Treatment burden is conceptualized as both the “workload and impact of treatment regimens on function and wellbeing” (Demain, et al., 2015, p.1).

In other words, the money, time, and energy spent managing chronic illness or mental health problems are viewed as consequential for engaging in treatment. The burden of treatment for children extends to caretakers, who cite financial burden and time commitment as some of the most challenging aspects of treatment (Sav et al., 2013). Unfortunately, when treatment is perceived as overly demanding, (i.e., costly and time consuming), parents are less likely to adhere to behavior interventions for their child with ASD (Carlon, Carter, & Stephenson, 2013). In addition to the financial means, there are aspects of accessing treatment which create further burden for parents. For example, a high number of weak or stressful connections with service systems is related to both high parent stress and high burden on families with a child with ASD (Kuhn, Ford, & Dawalt, 2018). Thus, an overly burdensome treatment modality may cause undue stress on caregivers as their engagement with it increases. As such, treatment burden may moderate the relation between adherence and parent stress, with adherence associated with decreased parent stress only when the perceived treatment burden is low.

Treatment relevance. Treatment relevance refers to parents' perception that the given treatment is what is needed to achieve desired outcomes. As a construct, the relevance or irrelevance of a given treatment largely influences whether a parent will attend psychotherapy for their children (Kazdin, et al., 1997). Furthermore, treatment relevance carries the most weight in the Barriers-to-Treatment model, as it had the largest effect on treatment participation in the 1997 study. Stevens, Kelleher, Ward-Estes, and Hayes (2006) extended these findings to non-research-oriented clinics and found that perceived treatment irrelevance to be one of the most consistent predictors of premature dropout from child psychotherapy.

Treatment relevance is an important consideration in the context of ASD treatment. Upon receiving an ASD diagnosis for their child, parents are often flooded with information about the numerous service options (Valentine, 2010), yet there is a hardly a guidebook for what therapies are necessary for whom, due to the heterogeneity of the disorder. Nonetheless, behavior intervention remains the “gold-standard treatment” for ASD (Masi, DeMayo, Glozier, & Guastella, 2017). Research has found that parent involvement in behavior treatment is significantly correlated with parents’ “belief in” treatment as essential to reduce problem behaviors related to ASD (Solish & Perry, 2008). Moreover, high expectations for behavior intervention are correlated with lowered levels of parent stress (Shepherd, Landon, & Goedeke, 2017). Thus, it would follow that parents who perceive their child is receiving the supports they need will experience reduced stress. For those involved in behavior treatment, the perceived relevancy of treatment may have a negative effect on parent stress. Parents may experience relief knowing their child is receiving the services he or she needs. In contrast, parents who feel their child’s treatment is disconnected from their child’s needs may feel more stress, which may ultimately lead them to be less engaged.

Treatment effectiveness. The perception of treatment effectiveness signifies the belief that a given treatment is producing desired therapeutic outcomes. The perception that a treatment *will be* effective is viewed by some as a necessary component of treatment engagement on the part of caregivers that leads to positive outcomes (King, Currie, & Petersen, 2014). By taking a “hopeful stance,” parents are in an optimal state of treatment engagement, and they are more likely to report therapeutic change (p. 4). Moreover, parents are more likely to adhere to or terminate behavior treatment for ASD

depending on perceived effectiveness of the intervention (Bowker, D'Angelo, Hicks, & Wells, 2011; Moore & Symons, 2011). When the belief of the effectiveness of a given treatment is low, parents experience heightened stress (Nock & Kazdin, 2001).

Conversely, when parents perceive a treatment to be effective, their levels of stress decrease over time (Hastings & Johnson, 2001). Thus, the degree to which adherence decreases parent stress may be strengthened by how effective parents believe the treatment to be.

The Present Study

Despite an increased focus on family-centered approaches to ASD treatment, there is a lack of understanding on how treatment involvement either alleviates or exacerbates parent stress. Fidelity of behavior treatment protocols is advantageous for child outcomes (Klintwall, Gillberg, Bölte, & Fernell, 2012), but it is unclear if the same influence exists for parent outcomes. Existing research has examined this relation through comparing groups by treatment type (Hastings & Johnsons, 2001; Shepherd et al., 2018) or by measuring stress as an outcome of an intervention (Rivard, et al., 2017). However, examining all possible values of variables is a necessary procedure for understanding associations (Moses, Emmerson, Hosseini, 1984), and it remains unknown whether high parent involvement results in the best outcomes for parents. Therefore, it is advantageous to explore a possible linear relationship between treatment adherence and parent stress. To the author's knowledge, there are no studies which have examined the role of treatment adherence as a predictor of parent stress. Because parent stress can hamper the effectiveness of behavior treatment, it is vital for parents to select treatment for their

children that not only addresses their child's needs but also indirectly impacts their own wellbeing.

There remains an incomplete understanding of the factors that attenuate the impact of behavior treatment adherence on parent stress. It has been shown that perceptions of treatment sometimes serve as barriers to treatment adherence and can exacerbate parent stress. However, the degree to which perceptions interact with treatment adherence to impact parent stress has not been investigated. A clearer picture of the interplay between treatment adherence and parent perceptions will fill a necessary gap in the literature by identifying which aspects of ASD treatment affect parent wellbeing. Understanding these relations will also allow clinicians to better understand how and why ASD treatment may create stress for other family members, which may negatively impact treatment outcomes. For stressed parents who are at risk for prematurely dropping out from their child's treatment, it is prudent to examine the factors that are amenable to change. Such perceptions of treatment—relevance, effectiveness, and burden—can inform intervention targets for clinicians, as well as decisions about treatment choice for parents.

The current study sought to address these two questions: What are the unique effects of behavior treatment adherence and perceptions on parent stress? Do perceptions of treatment (i.e., treatment burden, treatment relevance, and treatment effectiveness) moderate the relation between treatment adherence and parent stress? We hypothesize that (1) treatment adherence will have a significant negative relation with parent stress; (2) treatment relevance and treatment effectiveness will be negatively associated with parent stress, treatment burden will be positively related to parent stress; and (3)

perceptions of treatment will moderate the impact of treatment adherence on parent stress, with treatment relevance and treatment effectiveness strengthening the relation and treatment burden weakening it. These findings will address a gap in the current body of literature by teasing apart the associations between parent stress, treatment adherence, and perceptions of treatment.

CHAPTER 2: METHOD

Participants

The data were drawn from an existing dataset that comprised of a survey about treatment adherence in autism spectrum disorder. Two hundred and seventy participants returned the original survey, and 202 respondents reported that their child was currently receiving either home or center-based ABA, behavior therapy, and/or other type of behavior therapy. There were no significant differences in demographic variables between those who were involved in behavior treatment versus those who were not. Among those who were receiving behavior treatment, 2 participants reported that their child had either stopped ABA therapy or were still on a waiting list, and these were excluded from analysis. One participant reported that their child was seeing a psychologist and was removed because it was not specified that this was behavior therapy. Finally, 9 participants reported that their child received behavior therapy only at school and were also excluded from the analysis, as parents may not be expected to adhere to school-based behavior regimens.

A total of 158 mothers, 26 fathers, and 6 other caregivers (e.g., grandparent, aunt, uncle, older sibling, etc.) were included in the analysis ($N = 190$). Of those, 72.5% were White, 86.2% had some education past high school, and 56.1% were between the ages of 25-40. Inclusion criteria for the study included being a parent of a child with ASD who was currently receiving behavioral treatment. The sample primarily included parents of

whaschool-aged children with ASD (ages 6-12; 49%), closely followed by toddlers and preschoolers (ages 2-5; 34.6%) and finally adolescents (ages 13-17; 16.4%). Most parents (84.7%) reported on a male child with ASD. **Measures**

Treatment adherence. Treatment adherence to behavior therapy was collected through the General Adherence subscale of the Medical Outcomes Study (Rodriquez-Martinez, Sossa, & Rand, 2007). This measure was comprised of 5 items rated on a Likert-type scale to indicate self-reported adherence over the previous four weeks. An example item was, *'I followed my doctor/ provider/ therapist's treatment plan.'* The internal consistency reliability coefficient of the analytic sample, as indicated by Cronbach's Alpha, was .86.

Parent stress. Parent stress was measured by the Parenting Stress Scale (PSS; Berry & Jones, 1995). The PSS is an 18-item measure which assessed level of stress related to raising children. The measure included items which reflected negative outcomes of parenting (e.g., *'I feel overwhelmed by the responsibility of being a parent'*) and reverse coded items which reflected positive aspects (e.g., *'I enjoy spending time with my children.'*). The internal consistency was high ($\alpha = .89$).

Perceptions. Each of the 3 perception of treatment variables (i.e., treatment burden, treatment relevance, and treatment effectiveness) was measured by a single item. The items were measured on a Likert-type scale and were *'Behavioral treatments have been burdensome on my family's resources (e.g., money, time, energies),'* *'Behavioral treatments are consistent with what my child needs to improve,'* and *'I believe behavior treatments are effective for my child.'*

Child associated challenging behaviors (ACBs). Behavior problems were assessed through an inventory on the questionnaire, which was developed by the research team to maintain brevity of the larger survey. The items indicated aggression toward others, self-injurious behavior, anxiety, regulatory behavior, trouble reasoning or solving problems, and noncompliance, which are all ACBs that are associated with parent stress in the ASD literature (Lecavalier, Leone, & Wiltz, 2006). Parents rated the severity of each behavior on a scale ranging from 0 (none) to 4 (severe), and the total ACB score was computed as a sum of 6 items. For a detailed description of this measure, see Hock, Kinsman, & Ortaglia, 2015.

Demographics. Parent demographics included relationship to child, race, age, and education level, as well as their child's age and gender.

Procedures

Potential participants were recruited through mail and electronic surveys that were distributed in ASD clinics located in a Southeastern state. Additionally, paper surveys were sent to past and present recipients of a publicly-funded early intensive behavioral intervention program. Participants either returned the survey in a business reply envelope or followed the online link provided in the packet. The survey packet contained an informed consent letter, demographic questionnaire, study measures, and open-ended questions. All study procedures were approved by the investigators' Institutional Review Board. Participants received a 25 USD gift card upon completion of the measure.

Data Analysis

Descriptive statistics, correlations, tests of assumptions, and linear regression models were conducted using SPSS version 25. First, the mean, standard deviation,

range, and skewness of each variable were computed. To investigate possible relations between key variables and covariates, a bivariate correlation table was constructed for parent stress, ACBs, child age, treatment burden, treatment relevance, and treatment effectiveness. Next, separate linear regression models were constructed for each of the three perceptions of treatment. To accommodate for the behavior problems and parent stress relation, as well as potential age-related differences, ACBs and child age were included as covariates to control for the influence of behavior on parent stress. In the first step, the covariates, treatment adherence, and the treatment perception were included as predictors, with parent stress as the outcome. In this way, the main effects of treatment adherence and treatment perceptions on parent stress were examined. To investigate the potential moderating effect of each perception, an interaction term between treatment adherence and the perception was added as a predictor in the second step.

CHAPTER 3: RESULTS

Descriptive Statistics and Correlations

Tables 3.1 and 3.2 list the descriptive statistics and correlations for the study variables. The bivariate correlation matrix yielded significant correlations between parent stress and treatment adherence ($r = -.45, p < .001$), parent stress and treatment burden ($r = .27, p < .001$), and parent stress and behavior problems ($r = .32, p < .001$). Correlations between parent stress and both treatment relevance and treatment effectiveness were nonsignificant ($p > .05$). Treatment adherence was significantly correlated with treatment burden ($r = -.20, p = .007$) and treatment relevance ($r = .16, p = .03$), but not treatment effectiveness ($r = .18, p = .07$). Child age was significantly correlated with treatment effectiveness only ($r = .15, p = .04$)

Inferential Statistics

Assumptions of multiple regression were each met for each model. Visual inspections of the scatterplots of the residuals versus predicted values determined that the assumptions of normality, homoscedasticity, and linearity were met. The variance inflation factor (VIF) fell under 5 for each variable, which demonstrated that there was likely no multicollinearity among study variables (Mendenhall & Sincich, 2012).

Treatment burden. In Model 1, 29% of the variance in parent stress was explained, and treatment adherence ($\beta = -.38, p < .001$), treatment burden ($\beta = .19, p = .007$), and behavior problems ($\beta = .20, p = .003$) each had main effects. The interaction of treatment adherence and treatment burden ($\beta = .66, p = .04$) emerged as a significant predictor of parenting stress, and the model explained an additional 2% of the variance in parent stress, 31% total. Table 3.3 displays the linear regression models for all three perceptions of treatment.

A post hoc analysis was conducted to probe the significant interaction effect. A simple slope analysis (Aiken & West, 1996) was employed by constructing conditional effects plots (shown in Figure 3.1) to determine significance of slopes at both one standard deviation below and one above the mean of treatment burden. Treatment burden yielded significant slopes at both the high ($t = -6.18, p < .001$) and low ends ($t = -3.54, p < .001$). Because treatment burden was treated as a continuous variable, it can be concluded that the regression of treatment adherence on parent stress varied as a function of treatment burden.

Treatment relevance. Model 2 derived main effects of treatment adherence ($\beta = -.41, p < .001$) and behavior problems ($\beta = .25, p < .001$), but not treatment relevance ($\beta = .06, p > .05$). Further, 26% of the total variance in parent stress was explained. The interaction of treatment adherence and treatment relevance ($\beta = -.01, p > .05$) was not a significant predictor of parenting stress.

Treatment effectiveness. Results of Model 3 indicated main effects for treatment adherence ($\beta = -.41, p < .001$) and behavior problems ($\beta = .24, p = .001$), but not treatment effectiveness ($\beta = .05, p > .05$). The model explained 26% of the variance in

parent stress. The interaction of treatment adherence and treatment effectiveness ($\beta = -.05, p > .05$) did not emerge as a significant predictor of parenting stress in the second step.

Table 3.1

Descriptive statistics of key variables

Variable	<i>n</i>	<i>M</i>	<i>SD</i>	Range	
				Potential	Actual
Parent Stress	188	41.70	11.06	18-90	18-73
ACBs	183	13.80	3.90	0-24	6-24
Child Age	169	7.29	3.3	0-18	2-17
Treatment Adherence	179	4.50	1.05	1-6	1-6
Treatment Relevance	185	4.11	.92	1-5	1-5
Treatment Effectiveness	185	4.10	1.00	1-5	1-5
Treatment Burden	184	3.18	1.32	1-5	1-5

Note. ACBs= associated challenging behaviors.

Table 3.2

Bivariate correlation matrix of key variables

Variable	1	2	3	4	5	6	7
1. Parent Stress	-						
2. ACBs	.32***	-					
3. Child Age	.10	.01	-				
4. Treatment Adherence	-.45***	-.16*	-.10	-			
5. Treatment Relevance	-.10	-.23**	-.11	.16*	-		
6. Treatment Effectiveness	-.08	-.26***	-.15*	.14	.65***	-	
7. Treatment Burden	.27***	.06	.14	-.20**	-.02	-.02	-

Note. ACBs= associated challenging behaviors.

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

Table 3.3

Linear regression models using treatment adherence and perceptions to predict parent stress

Predictor	<i>B</i>	<i>SE</i>	β	<i>R</i> ²	ΔR^2
Model 1:					
Step 1				.29	
ACBs	.58	.20	.20**		
Child Age	.11	.23	.03		
Treatment Adherence	-3.95	.72	-.38***		
Treatment Burden	1.55	.56	.19**		
Step 2				.31	.02
ACBs	.56	.19	.20**		
Child Age	.15	.22	.04		
Treatment Adherence	-7.65	1.90	-.73***		
Treatment Burden	-3.57	2.49	-.43		
TA x TB	1.11	.66	.66*		
Model 2:					
Step 1				.26	
ACBs	.71	.21	.24**		
Child Age	.18	.23	.05		
Treatment Adherence	-4.29	.73	-.41***		
Treatment Relevance	.57	.85	.06		
Step 2				.26	.00
ACBs	.80	.51	.25		
Child Age	.20	.23	.05		
Treatment Adherence	-4.26	.73	-.41***		
Treatment Relevance	1.01	2.33	.07		
TA x TR	-.02	.09	-.01		
Model 3:					
Step 1				.26	
ACBs	.71	.21	.24**		
Child Age	.19	.23	.06		
Treatment Adherence	-4.27	.72	-.41***		
Treatment Effectiveness	.57	.79	.05		
Step 2				.26	.00
ACBs	.80	.49	.27		
Child Age	.20	.23	.06		
Treatment Adherence	-4.26	.73	-.41***		
Treatment Effectiveness	1.01	2.23	.09		
TA x TE	-.02	.09	-.05		

Note. ACBs= associated challenging behaviors; TA= Treatment Adherence; TB= Treatment Burden; TE=Treatment Effectiveness; TR=Treatment Relevance

p*<.05, *p*<.01, ****p*<.001

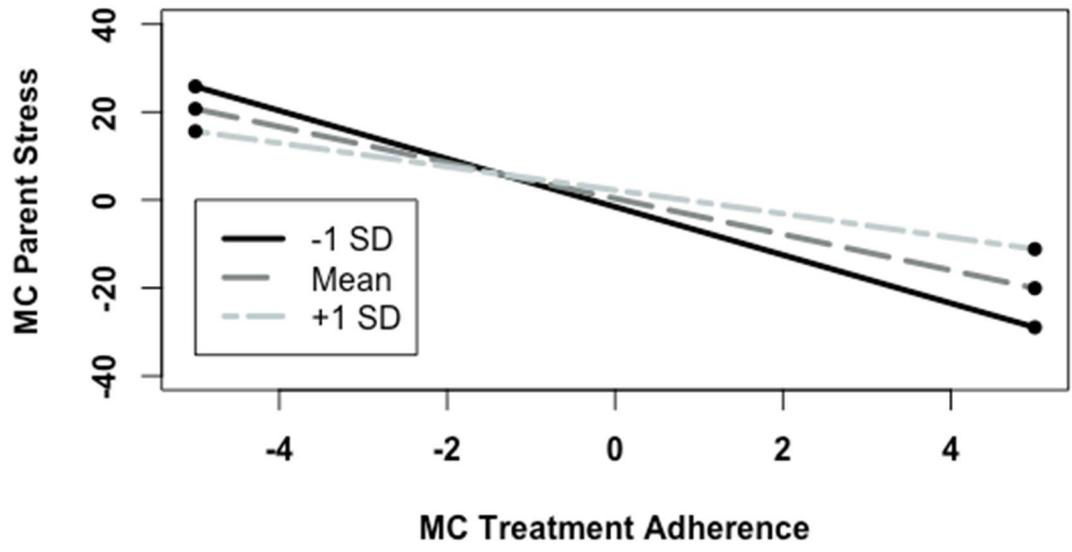


Figure 3.1. Conditional effects plot for simple slope analysis (Aiken & West, 1996) of parent stress regressed on treatment adherence and treatment burden at 1.) one standard deviation below the mean, 2.) the mean, and 3.) one standard deviation above the mean. All variables were mean centered to aid in ease of interpretation.

CHAPTER 4: DISCUSSION

This study aimed to understand how adherence to behavioral treatments for ASD influences parent stress, as well as to investigate the perceptions of treatment which may account for the stress. The findings suggest that high adherence to treatment was associated with lower levels of parent stress. After controlling for parent-reported behavior problems, only treatment burden emerged as both a predictor and a moderator for parent stress. Conversely, neither treatment relevance nor treatment effectiveness emerged as predictors or moderators in their respective models. Thus, it appears that higher treatment burden weakens the effect of adherence on parent stress, and a lower treatment burden strengthens the effect of adherence on parent stress. This study was one of the first to demonstrate that parent treatment involvement, as measured by adherence, is related to significantly lowered parent stress. In addition, few other studies have explicitly examined the moderating effects of treatment perceptions on parent stress.

In line with previous studies of parent involvement in ASD treatment (Hastings & Johnson, 2001; Shepherd, Landon, Goedeke, Ty & Csako, 2018), these findings highlight an association between behavior therapy and reduced parent stress. High adherence to behavioral therapy would presumably remediate the ACBs. Given the association between ACBs and parent stress in the context of family systems theory (Minuchin, 1985), it would follow that parent wellbeing would increase as a function of increased behavioral functioning in children. Nonetheless, it is important to note that the sample

only included families who were actively involved in behavioral treatment, and those who found it overly stressful may have self-selected out of the study and are not captured in the findings.

The second research question aimed to understand what perceptions of treatment may interact with adherence to influence parent stress. The hypothesis that treatment burden would emerge as a moderator was supported, which was expected given that high burden is related to stressful connections with ASD services (Kuhn, Ford, & Dawalt, 2018). Thus, although adherence can help with stress, relief varies by the extent to which the treatment is not overly burdensome. With the relatively high recommended dosage and intensity of ABA, as well as its expense (e.g., up to \$30,000 per year; Sharpe & Baker, 2007), it is unsurprising that time and money would have such adverse effects on parent stress as parents adhere to the treatment. Given these findings, it is prudent to inform parents that they may experience increased levels of stress related to the burden of engaging in behavior therapy.

There was insufficient evidence that perceived treatment effectiveness and treatment relevance moderated the relationship between treatment adherence and parent stress. These findings contradict the hypotheses as well as the available literature that these two perceptions are implicated with both stress and behavior treatment. It may be that these perceptions are not as salient to parent stress as was anticipated. Conversely, the sample was likely biased to include parents who already believed that the treatment was important for their child's needs and found it helpful. It is unlikely that parents would engage in treatment for very long if they did not find it relevant or effective.

Including more items to measure each treatment perceptions may give a clearer picture of how these constructs are related to parent stress.

Parents of children with ASD experience higher levels of stress compared to any other developmental disability (Hayes & Watson, 2013), in part due to the high number of associated challenging behavior problems. As parents take on the responsibility for ensuring their children are getting adequate treatment for ASD (Green, 2007), they are also frequently being trained in behavior treatment protocols. Behavior therapy continues to be one of the most utilized treatments for ASD, and it is necessary to understand how treatment adherence affects parent wellbeing. The findings from this study suggest that the case can be made for high treatment adherence to help with parent stress levels, provided that the burden is not too great. Furthermore, when making recommendations, clinicians should notify parents of the potential burden incurred by behavior treatment and take into consideration how it will affect their wellbeing.

Limitations and Future Directions

As is true of cross-sectional designs, it is difficult to ascertain the directionality of effects without further exploration. Given that parent stress reduces the effect of behavior treatment (Osborne, McHugh, Saunders, & Reed, 2008b), it may be just as likely that heightened stress leads to lower adherence rates. Future replication studies may employ a longitudinal design, so that the effect of adherence level on stress can be assessed across time. It may also be interesting to examine whether perceptions of treatment would mediate the effect on parent stress, as they shape how parents internalize the strain of ASD. Such perceptions may change over time as the treatment is either successful or unsuccessful.

Another limitation of this study was that it is not known whether the behavior treatment specifically targeted ACBs or other skills development, as both are frequent targets of behavior therapy. Consequently, it is unclear from these findings if the lowered stress was actually related to the success of treatment decreasing the ACBs. Future modeling of the long-term effects of treatment adherence should control for behavior change over time. Though the families were currently involved in ABA or behavior treatment, it is unknown how much parents were included in the treatment plan or if they were necessarily deliverers of the intervention. However, parents did report on whether or not they were implementing their part of the prescribed treatment protocol. Ultimately, one would hope that adherence leads to a decrease in both ACBs and, by consequence, parent stress over time.

The extent to which experiences with ASD treatment may differ among demographic groups is another consideration that warrants exploration. Our study found that burden moderated the adherence and stress association. It is known that different demographic groups experience unique stressors related to ASD and may be differentially affected by the burden of treatment. For example, African American children with ASD receive a diagnosis on average 1.6 years later than White children, and they require 3 times as many doctor's visits over a period of 3 times as long (Mandell, Listerud, Levy & Pinto-Martin, 2009). Whereas children from white families usually get diagnosed at medical centers, children from Black and Latino populations often do not get their diagnosis until they reach school. Such gaps in accurate classification create further disparities in the treatment outcomes, as the early intervention window may be missed (Tincani, Travers, & Boutout, 2009). Concurrent to these

disparities are the added stresses that members of disadvantaged communities face, including limited access to resources in general and systematic oppression. Given these group differences, it may be worthwhile to study how treatment burden and parent stress may differ by demographic category.

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