

Treatment Related Stress in Parents of Children with Autism Spectrum Disorder

by

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Abstract

Research reveals that parents of children with Autism Spectrum Disorder (ASD) have reported higher levels of stress compared to parents with typically developing children or children suffering from other illnesses (e.g., Giovagnoli et al., 2015). This parental stress is associated with higher occurrences of parental fatigue, heart disease and gastrointestinal ulcers along with feelings of reduced social support and marital satisfaction, among other consequences (Hayes & Watson, 2013; Hodgetts, Nicholas, & Zwaigenbaum, 2013). Previous literature suggested that problem behaviors, that often accompany ASD, are predictive of parental stress (e.g., Estes et al., 2009). Such parental stress can increase the risk for depression and anxiety as well as have other negative effects on parents. This exploratory, cross-sectional study examined predictors of parental stress in a sample of 50 parents of children with ASD that were currently receiving clinic-based ABA therapy. Participants were primarily recruited from five ABA clinics in a midwestern region and had the option of completing paper surveys or online. Specifically, child problem behaviors, perceived improvement through therapy, parent-therapist alliance, and perceived barriers to treatment were assessed for their contribution to parental stress. Results indicate that, indeed, problem behaviors were most predictive of parental stress. Parent-therapist alliance significantly adds to the variance in the model predicting parental stress, after accounting for problem behaviors. Perceived barriers to treatment were shown to partially mediate the relationship between parent-therapist alliance and parental stress. This study emphasizes the importance of the parent and therapist relationship for children's treatment.

Establishing supportive and honest relationships with parents can relieve parenting stress and in turn may allow parents to notice their child's treatment improvement as well as reduce problem behaviors that are a result of negative parent-child interactions. Additionally, when ABA clinics become aware of the barriers that parents experience, they could implement changes within their system to better serve their child patients and parents or provide more comprehensive care for families to address barriers.

Chapter I

Introduction

It is not surprising that the role of parenting and all the responsibilities that come along with being a caregiver often causes stress. The manner in which parental stress presents itself varies from family to family. The Lazarus and Folkman theory suggests that general stress results from an individual's, or a family's, interaction with the environment (Folkman & Lazarus, 1985). When their resources are overwhelmed by environmental stressors, they engage in coping skills in attempt to endure such stress (Folkman & Lazarus, 1985). Specifically, parental stress arises when individuals feel that their parenting demands outweigh their available resources and skills (Abidin, 1995). This feeling of excessive stress commonly is coupled with maladaptive coping mechanisms (Folkman & Lazarus, 1985). As noted by Hayes and Watson, the stress of parenting often causes distress or discomfort (2015). Parental stress is exacerbated when a family is unable to return to functioning using their normal coping strategies after the introduction of a stressor (Folkman & Lazarus, 1985). All parents will experience parental stress at times and some families will experience it more often than others.

Research reveals that parents of children with Autism Spectrum Disorder (ASD) have reported higher levels of stress compared to parents with children developing in a typical manner or those that suffer from other illnesses, such as cerebral palsy, Down's syndrome, intellectual disability, fragile x syndrome, and cystic fibrosis (Estes et al., 2009; Giovagnoli et al., 2015; Hsiao, Higgins, Pierce, Whitby & Tandy, 2017). High parental stress is associated with both

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negative physical and psychological effects. More so, a significant number of parents are impacted by the presence of this disorder in their children; about 1 in 59 children have been identified with ASD (Centers for Disease Control and Prevention [CDC], 2010) which some experts believe is an underestimate of the actual prevalence for ASD (Christensen, 2019).

Research has shown that ASD can be diagnosed reliably by age two, however, most individuals are not diagnosed until after four years of age. ASD has been reported in all ethnic, racial, and socioeconomic groups (CDC, 2010). ASD is 4 times more common in boys than among girls, but this sex disparity has been found to decrease as severity increases (Lyall et al., 2017).

Behaviors Faced by Parents of Children with ASD

Behaviors Defined as Autism Spectrum Disorder Criteria. Children with ASD display abnormal social interactions and communication skills across multiple contexts, which is the first of two broad diagnostic criteria, according to the DSM-5 (American Psychiatric Association, 2013). More specifically, children with ASD have deficits in social-emotional reciprocity; for example, failure to initiate or respond to social interactions, lack of back-and-forth conversation, and/or a lack of sharing interests or emotions with others. Nonverbal communicative behaviors often are lacking in ASD, ranging from abnormalities in eye contact, poor understanding and use of gestures, to a complete absence of facial expressions and nonverbal behavior. It is common for a child with ASD to have a difficult time understanding and maintaining relationships. This lack of relational understanding can present as having difficulty adjusting their behavior to fit certain social contexts, sharing in imaginative play, making friends, or can result in a complete lack of interest in peers (American Psychiatric Association, 2013).

The second broad diagnostic criteria states that a child with ASD has restricted or repetitive behaviors, activities, or interests presenting in at least two ways (American Psychiatric

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Association, 2013). One way a child with ASD may present this behavior would be with repetitive motor behavior such as lining up toys, copying phrases often, or hand-flapping. Further, an additional symptom of ASD is inflexible adherence to ritualized patterns or routines which can result in disproportional distress from small changes or transitions (American Psychiatric Association, 2013). This lack of flexibility is referred to rigid behavior. Fixated interests that are unusual in focus or intensity are another behavioral feature that falls under restricted or repetitive behaviors (American Psychiatric Association, 2013). Lastly, a sensitivity or unusual interest in sensory input, such as adverse responses to textures or sounds, visual fascination with lights, or excessive smelling of objects, can also be present. Such symptoms cause impairment in occupational, social, and other areas of human interaction (American Psychiatric Association, 2013). These ASD symptoms described above typically occur by age three, however, in milder cases it may be more difficult to identify and, thus, a diagnosis may not be given until a later age (Lyall et al., 2017).

Commonly Related Problem Behaviors. ASD is often accompanied by problem behaviors alongside of the social and communication skill deficits and restricted or repetitive behaviors (Matson & Nebel-Schwalm, 2005). Children with ASD have greater levels of socially problematic behavior than other developmental disorders, such as ADHD and intellectual disabilities. The presence of problem behaviors can further hinder socialization, activities, and other learning opportunities (Matson & Nebel-Schwalm, 2005). Food refusal and sleeping problems are two problem behaviors that are prevalent in the Autism population. Feeding problems are often linked to extreme food sensitivities which results in an interest of a few specific food textures (Matson & Nebel-Schwalm, 2005). In severe cases, feeding problems can lead to malnutrition and dehydration (Kodak & Piazza, 2008). Among these feeding problems,

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Pica, the ingestion of non-food items, is considered one of the most significant self-injurious behaviors as it can result in surgery to remove the item, repeated hospital visits, introduction of a disease into the body, lead poisoning, and in some cases even death (Kodak & Piazza, 2008).

Difficulties falling asleep, staying asleep, and waking early are frequent problems for individuals with ASD, especially children. Sleeping problems generally are associated with difficulties concentrating, learning, behavioral problems, and irritability. It is hypothesized that children with ASD react more emotionally and have a more difficult time with social interactions as a result of a lack of sleep (Kodak & Piazza, 2008).

Aggressive behavior and self-inflicted injuries are common problem behaviors in both intellectually disabled individuals, as well as in ASD individuals (Matson & Nebel-Schwalm, 2005). While aggression is present in other developmental disabilities as well as in the general population, there are higher prevalence rates for aggression in individuals with ASD (Matson & Rivet, 2008). Property destruction and/or aggressive behavior against others has been reported to occur at some point in their lives for 67% of ASD individuals (Lecavalier, 2006). A few consequences of aggressive behaviors are that these behaviors are likely to become more severe with time if untreated, are physically dangerous to the individual and other individuals in their environment, can impede learning opportunities, and might limit access to residential and respite programs (Hodgetts, Nicholas, & Zwaigenbaum, 2013).

Another behavioral aspect of ASD is self-injurious behaviors by the individual which may cause harm to their own bodies; for example, head-banging or teeth grinding (Matson & Nebel-Schwalm, 2005). Similar to aggressive behaviors, a greater percentage of people with ASD engage in self-injurious behaviors than typically developing individuals and those with neurodevelopmental disorders (Gulsrud, Lin, Park, Hellemann, & McCracken, 2018). These

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maladaptive behaviors are one of the leading reasons for intensive healthcare, such as ER visits, for individuals on the Autism spectrum (Gulsrud, Lin, Park, Hellemann, & McCracken, 2018). One study found that an ASD diagnosis significantly predicted the occurrence of self-injurious behavior later in life (Gulsrud, Lin, Park, Hellemann, & McCracken, 2018).

Lastly, stereotypies often are striking characteristics of autism. The most frequently discussed are rhythmic rocking, hand flapping, and twirling objects directly in front of the eyes (Matson & Nebel-Schwalm, 2005). The stereotypical behaviors can be described as repetitive actions in response to stimuli, which is a non-adaptive response, especially when in social situations. Although stereotypies are often considered the least problematic in comparison to aggression and self-injury, they have been found to be a precursor to self-injury and frequently inhibit skill acquisition (Matson & Nebel-Schwalm, 2005).

Parenting Stress and Child Problem Behaviors

Parental stress has been found to be more strongly associated with these behavioral problems (i.e., aggressive, destructive, and self-injurious behavior) described herein than the severity of diagnostic criteria, social and communication deficits along with restrictive or repetitive behavior, in children with ASD (e.g., Estes et al., 2009; Giovagnoli et al., 2015). Giovagnoli and colleagues found aggressive behavior significantly accounted for the most variance in parental stress in those with preschool aged children with ASD (2015). Parents whose children are aggressive have been found to have increased feelings of stigmatization and increased isolation (Hodgetts, Nicholas, & Zwaigenbaum, 2013). Similarly, parents of children with ASD that engage in self-injurious behaviors report a lower quality of life as the severity of the behaviors increases (Gulsrud, Lin, Park, Hellemann, & McCracken, 2018).

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Examining and analyzing parental stress is essential for seeking new and better ways to reduce the negative effects stress can have on a parent, both physically and psychologically. Common physical effects from significant amounts of stress include fatigue, restlessness, increased risk for heart disease and ulcers (Hayes & Watson, 2013). Additionally, these parents are at increased risk for marital discord, decreased parenting satisfaction and decreased social support (Hodgetts, Nicholas, & Zwaigenbaum, 2013). These negative effects dramatically impact the well-being of the parents which may increase their level of burnout (Chan, Lam, Law, Cheung, 2018). Additionally, parental stress can disrupt parenting behavior which in turn adversely impacts the parent-child relationship (Davis & Carter, 2008; Estes et al., 2009). Daily parenting hassles and stressful life events have been shown to predict future problem behaviors and have a negative effect in typical developing preschool children over two years (Davis & Carter, 2008). Furthermore, a bi-directional relationship has been found between a child's problem behaviors and parental stress, leading to an increase in the child's problem behaviors in both typically developing children and those with developmental disorders, including ASD (Hwang, Kearny, Klieve, Lang, & Roberts, 2015). Poor sleep, which is particularly notable for parents of children with frequent problem behaviors, is associated with a caregiver's inability to contain their irritability, thus placing the child at higher risk for maltreatment (Kodak & Piazza, 2008).

The literature has found that parents of children with ASD also have higher incidences of depression and anxiety (Hayes & Watson, 2013). Parental depression has been associated with higher reports of problem behaviors in both typical developing children and children with ASD (Davis & Carter, 2008), insinuating that parents are more distressed by their child's behavior once they are depressed. As can be surmised, the negative impact of parental stress on the

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children in an already challenging environment impacts the behavior of the children. We are proposing that the investigation of sources of parental stress within a treatment setting may help to reduce familial stress with a goal to improve the lives of families dealing with ASD.

Impact of Therapeutic Intervention and Related Behavioral Changes on Parental Stress

Perceived Improvement as Potentially Related to Parental Stress. Research examining adults receiving mental health services suggests an association between a patient's life satisfaction with their unmet needs (Slade, Leese, Cahill, Thornicroft, & Kuipers, 2005). The authors defined a client's "needs" as: psychological distress, a lack of information about their condition, the absence of recommended treatment, safety, childcare, and transportation, to name a few. The literature also demonstrates that reducing the number of patient-rated unmet needs was associated highly with an improvement in quality of life (Slade, Leese, Cahill, Thornicroft, & Kuipers, 2005). Similarly, others found that unmet needs alone accounted for a significant amount of the variance for an individual's quality of life (e.g., Slade, Leese, & Taylor, 1999; UK700 Group, 1999). The effectiveness of reducing unmet needs via mental health treatment is one way to measure the effectiveness of mental health treatment. In other words, research suggests that effective mental health treatment improves a patient's quality of life. Although quality of life is separate from stress, the literature has shown a strong negative relationship between parental stress in those with a child with ASD with their family's quality of life (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017).

For parents of children with ASD, their "needs" and "quality of life," are likely closely aligned with their child's condition and related treatment. Treatment for autism typically aims to improve communication, social skills, and to reduce challenging behaviors. Because previous literature suggests that the exhibition of challenging behaviors is one of the most significant

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stressors for parents with a child with ASD (e.g., Estes et al., 2009; Giovagnoli et al., 2015), one might expect that improving these behaviors will decrease parental stress.

Use of Applied Behavioral Analysis Therapy for ASD and Related Behavior

Problems. Applied Behavioral Analysis (ABA) therapy, a gold standard therapy for ASD, focuses on reducing or controlling challenging behaviors, developing social skills, and when appropriate, integrating the client into mainstream schools (Grindle, Kovshoff, Hastings, & Remington, 2009). ABA strives to be effective in producing significant behavioral changes that have practical value and ensure that a behavioral change is durable over time and across other settings, resulting in generality of the behavior (Ringdahl, Kopelman, & Falcomata, 2009). ABA was created using B.F. Skinner's operant conditioning principles. These principles emphasize shaping behavior in an organism or individual through the interaction with the environment. The 'applied' portion of ABA refers to addressing behaviors that are important to society, and specifically to the subject being studied, rather than to the theory itself. Therefore, the range of behaviors ABA can address varies widely and based on individual needs (Ringdahl, Kopelman, & Falcomata, 2009).

ABA assesses behaviors that can be measured reliably by multiple observers and attempts to determine events responsible for the resulting behaviors (Ringdahl, Kopelman, & Falcomata, 2009). By determining the events responsible for the behavior, clinicians are able to use reinforcements within the environment to increase or reduce the frequency of such behaviors. Positive reinforcement delivered immediately after a response has been shown to increase various behaviors. Similarly, removing a negative stimulus in response to undesired behaviors can also increase desired behaviors. Alternatively, removing a positive reinforcer or adding a negative reinforcer will have the opposite effect and should reduce an undesired behavior. ABA

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therapy has many additional nuances to shape behavior all based on operant conditioning which can be further explored in Ringdahl, Kopelman, & Falcomata's chapter on the application of ABA to Autism (2009). The results from a meta-analysis on early intensive behavior intervention indicated that those in the intervention group outperformed children receiving other treatments (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). The intervention group moderately surpassed the control group on daily living skills and was noted to have a larger effect on IQ, nonverbal IQ, adaptive behavior, and receptive and expressive language as compared to control subjects (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). Howard and colleagues found that after one year of intervention, those receiving intensive ABA therapy had higher mean scores on assessments of adaptive and motor, cognitive, and language skills than the other treatment groups (2014). These results were consistent after two more years of maintaining treatment (Howard, Stanislaw, Green, Sparkman, & Cohen, 2014). In addition, early ABA therapy for children with ASD has been shown to be effective in multiple contexts such as in homes, clinics, and classrooms (Leaf, Leaf, McEachin, Cihon, & Ferguson, 2018). ABA based treatment is being investigated in this study in relation to parental stress as it has been shown to be effective for changing behavior in children with ASD (e.g., Howard, Stanislaw, Green, Sparkman, & Cohen, 2014; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011), and thus may impact parental stress in a positive way.

Additional prior research suggests that ABA treatment has an impact beyond the behavior of the child itself. For example, accounts from nine families receiving 20 hours per week of ABA in-home services for two years revealed a reduction in parental stress, compared to families receiving no treatment (Birnbrauer & Leach, 1993). Similarly, a qualitative study exploring parents' experience with ABA described that the improvement in family life was dramatic and

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significant, with reports of lower stress levels, providing a better quality of life and a more positive outlook for the future of their child (McPhilemy & Dillenburger, 2013). Furthermore, parents stated that the ABA intervention had a positive impact on their child's communication skills, challenging behaviors, and parental dependence which allowed for more manageable family outings and an improvement of overall quality of life for the family as a whole (McPhilemy & Dillenburger, 2013). Another study, however, indicated no difference between control and intervention families' stress ratings (Smith, Groen, & Wynn, 2000). Previous literature would suggest that in-home ABA programs either maintained parental stress at a constant level or reduced parental stress (Grindle, Kovshoff, Hastings, & Remington, 2009; Smith, Buch, & Gamby, 2000).

To our knowledge, however, there is no study directly assessing how parental stress is impacted by treatment-based improvement for children that attend clinic-based ABA therapy. Some studies do, however, explain some advantages and disadvantages to a clinic-based model opposed to children receiving ABA in their homes (Leaf, Leaf, McEachin, Cihon, & Ferguson, 2018). Some advantages of receiving services in a clinic include, but are not limited to: a staffing community that can help maintain therapist skills which could increase the effectiveness and fidelity of the intervention; supervisors who can observe sessions more frequently; a group environment is more closely related to how typically developing children are taught; there are much more social opportunities for clients to practice their social skills; and lastly, parents have the ability to connect with other parents at drop-off and pick-up times which could reduce feelings of isolation and loneliness. Some disadvantages to clinic-based treatment are: the cost of such treatment, difficulty generalizing skills to other contexts outside of the clinic, parents not being as involved with treatment compared to a home-based model, and the fact that parents are

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responsible for transporting their children to and from the clinic which often creates logistical difficulties for the parents (Leaf, Leaf, McEachin, Cihon, & Ferguson, 2018). These advantages and disadvantages suggest that parental stress could be impacted either positively (i.e., connecting with other parents) or negatively (i.e., transporting children to therapy) using a clinic-based treatment option.

The relationship between child treatment outcomes and parental stress may be bi-directional. The literature has indicated that parental stress does have an effect on child treatment outcomes in multiple disease states (e.g., Carlson-Green, Morris, & Krawiecki, 1995; Osborne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991). For example, two studies found a negative relationship between parental reported stress levels and treatment outcomes for typically developing children (Davis & Carter, 2008), children that had undergone treatment for pediatric brain tumors (Carlson-Green, Morris, & Krawiecki, 1995) and children with ASD receiving family-oriented education program (Robbins, Dunlap, & Plienis, 1991). Osborne and colleagues conducted a study to determine whether these results can be generalized for teaching interventions for ASD children (2008). The results indicated that there was a negative relationship between parental stress, which was assessed prior to beginning the intervention, and educational and adaptive behavior outcomes in those undergoing a mixture of reinforcement-based, special nursery, speech and language, and parent education treatment (Osborne, McHugh, Saunders, & Reed, 2008). The assessment of parental stress prior to the intervention seems to indicate more than just a correlational relationship (Osborne, McHugh, Saunders, & Reed, 2008). The present study aims to understand if, similar to this study, there is a relationship between parental stress and childhood improvement, including whether or not perceived treatment outcomes are predictive of parental stress.

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Although ABA therapy has shown to be effective, the literature is inconclusive whether these treatments might actually reduce parental stress. Particularly it is neither clear whether parents find it stress relieving to believe their child's problem behaviors are improving nor is it clear whether a lack of perceived improvement in the child, is associated with higher parental stress. Because one of the aims of ABA therapy is reducing problem behaviors, and those behaviors were shown to be a significant contributor to parental stress, we anticipate that perceived treatment improvement would be particularly beneficial to these parents.

Treatment Variables Potentially Related to Parental Stress

Therapeutic Alliance. The concept of alliance emerged in psychodynamic literature and is still considered to be a vital part of treatment approaches (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). Carl Rogers, known for his person-centered approach within the humanistic model, suggested that the quality of the therapeutic relationship was the main agent of change for individuals in therapy (Green, 2006). Since Roger's work, multiple terms have been used to describe alliance such as working alliance, helping alliance, and therapeutic alliance (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). Bordin (1979) created a definition of "alliance" that could be used across treatment approaches and includes three components: affective bond between client and professional, agreement between client and professional about treatment goals, and the agreement on tasks that need to be accomplished to reach treatment goals (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). In agreement with Bordin's definition is a more recent conceptualization of alliance which focuses on the affective and collaborative nature of the client-professional-relationship (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). More specifically, therapeutic alliance is typically broken down into 2 main parts: "personal alliance", which emphasizes the interpersonal

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relationship, and “task related alliance” which emphasizes shared goals and methods of treatment (Hougaard, 1994).

Current literature supports the notion and benefit of therapeutic alliance. In the literature concerning adult patients, the quality of client-professional alliance has been found to predict outcomes, no matter the type of treatment (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). Regardless of whether the client or the therapist reported the alliance ratings, a recent meta-analysis of 79 adult studies concluded that there is a modest and statistically significant positive relationship between alliance and treatment outcomes (Green, 2006). Much less research, however, has been conducted on the importance of therapeutic alliance in children and adolescent populations (Kazdin & McWhinney, 2018). A meta-analysis examining the effects of child and youth alliance with the therapist indicated that the alliance was a predictor of treatment outcome (Shirk, Karver, & Brown, 2011). However, due to a small number of studies examining alliance in children and youth, the effect sizes were small. Another study found that although children with externalizing disorders receiving in-patient therapy have a poorer prognosis, stronger child alliance with the professionals is indicative of treatment improvement (Green, 2006). Lastly, Kazdin and Durbin studied children with oppositional and anti-social behavior and found that the greater the quality of the child-therapist alliance, the greater the therapeutic change was (2012). Although the research is limited, therapeutic alliance for children and youth does seem to impact intervention and could be explored further.

It is common knowledge that very few children or adolescents initiate their own psychological treatment (Green, 2006); most often the parents or caregivers that initiate treatment on behalf of a child. In general, parents and caregivers feel a deep responsibility to promote a child’s social, physical, and emotional development, which includes initiating

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treatment, and, therefore, they play a large role in treatment for their child (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). The parents or caregivers often are the ones to find and seek out treatment, help motivate the children to participate, encourage adolescents to stay involved in treatment, and continue promoting positive behaviors in order to encourage outcomes in everyday life (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). This information suggests, therefore, high value in investigating the parent and therapist alliance in the context of the treatment in children.

The majority of current literature concludes that parent-professional alliance is positively related to improved clinical outcomes and lower drop-out rates (e.g., de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017; Kazdin & McWhinney, 2018). A meta-analysis examining children, youth, and parental alliance with the professional, found similar outcomes (Shirk, Karver, & Brown, 2011). The parent-professional alliance was a positive predictor for improved treatment outcomes in a child-focused treatment (Shirk, Karver, & Brown, 2011). As the present study examines ABA therapy, a child-focused treatment, as opposed to addressing child concerns with therapy for the parents or caregivers, this finding gives reason to continue exploring the parent-professional alliance. Kazdin and McWhinney also found that the stronger and better the parent-professional alliance was, measured both by the parent and the therapist, the greater the changes were at the end of treatment (2018). Prior to starting treatment, parents were assessed on their quality of life and their interpersonal relationships. Both higher quality of life scores and stronger interpersonal relationships (including friends, partners, and family) were predictive of stronger alliance with therapists, when alliance was rated by therapists but not by parents (Kazdin & McWhinney, 2018). It is important to recognize the effect that extraneous and pretreatment factors may have on therapeutic alliance; however, this study is inconclusive with

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regard to how much of an impact these factors have. The benefits of a strong parent-professional relationship, specifically the better treatment outcomes for the children, have been found in some of the literature.

In contrast, multiple studies also indicate that there is not an association between parent-therapist alliance and treatment outcomes (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017). One of the studies included in de Greef and colleagues' meta-analysis, examined the child and parent-professional alliance within multiple types of treatment (McLeod, 2011). Neither the parent- nor child-alliance were significantly associated with positive clinical outcomes. The authors did investigate multiple factors to determine which variables mediate alliance; factors such as age of the child, source of who completed the alliance questionnaire, outcome factor assessed, and the treatment mode, to name a few. The client's functioning was measured post-treatment and had a small effect in mediating the relationship between alliance and clinical outcomes. Individualized therapy had significantly higher alliance ratings than family therapy, although the effect size was still considered small (McLeod, 2011). Nonetheless, these findings support further examination of therapeutic parent-therapist alliance, and the parents perceived treatment improvement within the one-on-one ABA therapy modality.

As stated, research to date is unclear as to the impact that alliance has on clinical outcomes, specifically alliance pertaining to parents or caregivers in situations of child treatment. One study, examining a child's outcomes for an early intervention for physical therapy demonstrated the importance of the parents' satisfaction with the therapist and the control they had over the services and the goals for their child (Broggi & Sabatelli, 2010). Parents that had feelings of high control and satisfaction, labelled as a "collaborative type", had significantly lower parental stress than parents in the "distant type", low feelings of control and satisfaction

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(Broggi & Sabatelli, 2010). Although a different type of therapy, these results are promising, considering that the different relationship types map quite well onto the definition of working alliance for showing an association between parent-professional interaction, mentioned previously.

In the proposed study, we are interested in looking at how parent-therapist alliance can impact parental stress within the ASD population. Furthermore, the benefits of strong parent-professional alliance could be associated with better clinical outcomes (e.g., Kazdin & McWhinney, 2018), less externalizing behaviors (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017), and in some cases, better maternal functioning (Davis, 2007). Therefore, we see value in investigating such a relationship.

Barriers to Treatment. It is not surprising that children who require mental health care services often do not receive the treatment they need and of those that do receive services, as many as 75% of child clients drop out of treatment prior to the planned conclusion of treatment (Colonna-Pydyn, Gjesfield, & Greeno, 2007). Individuals from lower socioeconomic backgrounds and minority groups may be even less likely to receive services due to a number of considerable barriers (Colonna-Pydyn, Gjesfield, & Greeno, 2007). Researchers have been interested in the impact that barriers have on continuing care, along with the role that barriers play in high treatment drop-out rates. Less focus has been placed on what psychological and physical challenges clients may face in seeking therapy and how that could affect treatment progress or other treatment variables, such as therapeutic alliance (Karver, Handelsman, Fields, & Bickman, 2005). By studying and understanding these barriers, outcomes of related research can help providers plan and distribute mental health resources in order to reduce the personal and social burden of mental health illness (Andrade et al., 2013), predict session cancellations,

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premature drop-outs, and ultimately enhance therapeutic effectiveness (Kazdin & McWhinney, 2018).

Unlike many childhood medical conditions, specific causes of mental illnesses in children are often unknown, which is a barrier within itself for children receiving treatment (Owens et al., 2002). The mental healthcare system has many separate services that all have different approaches to program entry, funding sources and ultimate goals. In addition to these difficulties, mental health is still negatively stigmatized which may discourage individuals from utilizing existing services (Owens et al., 2002). Similar to extraneous factors that predict therapeutic alliance, perceived barriers are also predicted by other factors, for example, decreased quality of life for parents and increased psychopathology for parents (Kazdin & Wassell, 2000). These barriers impacted retention rates for child outpatient services (Kazdin & Wassell, 2000).

Barriers to mental health treatment are often conceptualized into separate categories: attitudinal barriers and structural barriers (e.g., Andrade et al., 2013; Owens et al., 2002). Attitudinal barriers are either perceptions about individual mental health problems or about mental health services. Things such as the denial of need for mental health services with a rationale that a mental health problem can be handled without formal services, a lack of trust with mental health care providers, or a perceived stigma related to receiving care are considered attitudinal barriers (Andrade et al., 2013; Owens et al., 2002). Research regarding individual barriers to receiving treatment for themselves or for their children, has shown that the attitudinal barriers, wanting to handle their problems on their own or not perceiving the need for treatment, dissatisfaction with service, and negative experience with a treatment provider, are significant barriers to treatment (Andrade et al., 2013). Attitudinal barriers were found to be associated significantly with additional responsibilities that take up time, difficulties with parenting,

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parental stressors such as being unemployed or having a disability, along with being divorced (Owens et al, 2002). An individual's high score on attitudinal barriers may suggest that their expectation of treatment did not match the actual process, either because of unrealistic expectations or that the treatment was not adequately outlined to the client (Colonna-Pydyn, Gjesfield, & Greeno, 2007).

Structural barriers are considered to be external difficulties such as long waiting lists, inability to pay for services, lack of availability of providers, transportation services, and inconvenient locations for treatment (Andrade et al., 2013; Owens et al., 2002). Significant structural barriers may be indicative of a more chaotic lifestyle and a difficulty to find time for treatment (Colonna-Pydyn, Gjesfield, & Greeno, 2007). Of the structural barriers, lack of availability, finances (Andrade et al., 2013; Edlund et al., 2002; Olfson et al., 2009), competing responsibilities for time, and difficulties with parenting significantly contributed to the high treatment dropout rates (Owens et al., 2002).

For both individuals that perceived the need for mental health services and those that never indicated a need for treatment, the reasons for dropping out of treatment were predominantly related to attitudinal reasons (Andrade et al., 2013), such as wanting to handle the illness on their own and perceived treatment ineffectiveness (Andrade et al., 2013). Described barriers relate back to perceived treatment improvement; it is possible that if parents become more aware of their child's improvement, whether that means a change in treatment or clinicians increasing the communication regarding a child's improvement to their parents, could reduce treatment drop-out rates and decrease parental stress.

Kazdin and McWhinney examined perceived barriers in the context of treatment for children and identified that the therapeutic alliance between the parent and therapist, along with

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fewer perceived barriers during treatment, were associated with greater changes at the end of treatment (2018). Furthermore, the perceived barriers and therapeutic alliance were moderately related, but each made a separate contribution to improving the prediction of therapeutic change (Kazdin & McWhinney, 2018).

In a post-assessment of parents that brought their child to therapy for anxiety, the most commonly endorsed perceived treatment barrier was stress in their life (Salloum, Johnco, Lewin, McBride, & Storch, 2016). This finding was a result of using the Barriers to Treatment Participation Scale (BTPS; Kazdin Holland, Crowley, & Breton, 1997; Salloum, Johnco, Lewin, McBride, & Storch, 2016). Additionally, the total score on the BTPS was significantly correlated to parent stress in two studies assessing parents who brought their child into behavioral therapy for oppositional, aggressive, and antisocial behavior (Kazdin & McWhinney, 2018; Kazdin, Holland, Crowley, & Breton, 1997).

As literature has shown that perceived barriers do impact whether or not individuals receive any treatment, drop-out rates, and therapeutic change, we are interested to examine the impact perceived treatment barriers have on parental stress itself in those whose children are currently receiving ABA therapy. It is probable that some parents are overwhelmed with their child's difficulties and a lack of resources, along with barriers to healthcare treatment which may ultimately prevent families from receiving care or affect their ability to stay in therapy (Owens et al., 2002). It is also possible that overwhelmed parents are more sensitive to the perception of barriers (Owens et al., 2002).

Hypotheses

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The aim of the present study is to assess how child behavior problems, perceived child improvement, parent-therapist alliance, and perceived treatment barriers are related to the stress experienced by parents of children with Autism Spectrum Disorder experience.

1. All of the factors will significantly relate to parental stress. Specifically, behavioral problems and perceived barriers will be positively correlated with parental stress, while perceived improvement and therapeutic alliance will be negatively correlated.
2. Problem behaviors will account for the most variance in parental stress, but the remaining factors will also significantly predict parental stress.
3. Perceived child improvement and perceived treatment barriers will mediate the relationship between parenting stress and parent-therapist alliance which will clarify and strengthen the relationship.

Chapter II

Methods

Participants

Despite a power analysis suggesting a sample size of 89, only fifty primary caregivers of children with ASD who were receiving clinic-based ABA therapy were surveyed using the tool described herein. Thus, the results should be considered preliminary analyses. The sample was overwhelmingly both female and mothers, 86% ($n = 43$), and the remaining were males and fathers, 14% ($n = 7$). The children of those sampled were predominantly males (86%, $n = 43$) as compared to females (14%, $n = 7$). In order to be eligible, all participants had to be 18 years or older, consistent with our consent requirements, and all the children in the samples were 18-years-old or younger. The age of the parents ranged from 23- to over 48-years-old, the majority of which fell between ages 33 and 42. The caregiver's children ranged from the ages 2 to 18; 40% of the children were within the ages 2 to 4. In terms of ethnicity, the sample was predominantly white (84%), followed by African American (10%), individuals identifying as multiracial (6%), American Indian or Alaska Native (2%), and Middle Eastern or North African (2%).

The majority of the participants were recruited from autism centers in the midwestern region. As a result of posting this study on the AutismSpeaks.Org website, two participants were recruited from outside the Midwest; one of the participants resided Pennsylvania and the other in Canada. Within the sample, 34 % ($n = 17$) received ABA services once a week or less, and 66%

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($n = 33$) received ABA services two to five times a week. All children had been receiving ABA treatment for a minimum of 3 weeks up to a maximum of 6 years ($M = 23.12$ months, $SD = 21.48$ months). Furthermore, 34% of the children had additional services, such as social skills group, parent child interaction therapy, physical therapy and occupational therapy.

Procedure

The principal investigator visited five clinics to recruit parents and caregivers while they were dropping off their children for ABA therapy. Parents were approached and introduced to the study while in the waiting room by the principal investigator. Interested participants had the choice of completing a paper-copy of the surveys or an electronic version accessed through a Qualtrics survey link provided through email. Both the paper copy and the online survey included an informed consent, a demographic form, and the five surveys. Participants were required to separately provide contact information if they wished to receive compensation for participation, which consisted of a \$10 Visa gift card funded by a grant received through the University of Michigan's Office of Research and Sponsored Projects office. For those completing the hard copy of the survey, two envelopes were given to participants to ensure that their names and contact information could not be connected to their survey answers. The principal investigator received the paper survey copies and contact information from a secured faculty mailbox at her university. Similarly, participants completing the online survey were instructed that upon completion, they would be directed to a separate form asking for their name and address. Neither the envelopes containing the surveys, nor the online surveys and related contact information, were opened until 10 were collected to protect participants' confidentiality.

Additionally, recruitment flyers were placed at all of the autism centers from which participants were recruited. These flyers explained the study and included the principal

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investigator's email information for caregivers that were not present when the recruiter was at the clinic (see Appendix A). Three clinics (two of which were visited by the PI and one which was not), also sent out an email to the parents of their clinic. Their email gave a brief explanation of the survey and provided the online link. This email was used as a follow-up in order to increase the number of participants. Approval to conduct this study was given by a University of Michigan's Institutional Review Board.

Measures

Parental stress. The 36-item Parenting Stress Index – Short Form (PSI-SF; see appendix B) – was derived from the full Parenting Stress Index and was created to shorten the administration time (Abidin, 1995). The scale consists of statements pertaining to stress related to the individual's child (e.g., “My child rarely does things for me that make me feel good”) and was used to assess the parent's stress levels. The survey tool is made up of three subscales: Difficult Child Characteristics, Parent-Child Dysfunctional Interaction, and Parental Distress. Additionally, 7 items from the scale make up a “Defensive Reporting” score. These 7 items (1, 2, 3, 7, 8, 9, and 11) are not included in the calculation for participants' total stress score. Parents rated their agreement with each item on a Likert scale ranging from one (strongly agree) to five (strongly disagree). Participants' higher total scores and mean scores for this measure, indicate higher levels of parental stress. The PSI-SF has been found to have good consistency ($r = .94$) with the original Parenting Stress Index (Abidin, 1995). Our sample had high internal consistency on the PSI-SF ($\alpha = .94$).

Problem behaviors. The 30-item Behavior Problems Inventory – Short Form (BPI-S; see appendix C) is an informant-based behavior rating measure used to assess a child's problem behavior, specifically self-injurious behavior, stereotyped behavior, and aggressive/destructive,

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in the past 6 months (Rojahn et al., 2012). Responses for the frequency of the occurrence of these behaviors utilized a five-point frequency scale (0 = never, 1 = monthly, 2 = weekly, 3 = daily, 4 = hourly). Additionally, the severity of the problem was ranked on a three-point scale (1 = mild, 2 = moderate, 3 = severe). Caregivers only rated the frequency, not severity, for stereotyped behavior. The BPI-S has indicated strong sensitivity and a high correlation with each of the subscales from the original Behavior Problems Inventory (Rojahn et al., 2012). Internal consistencies were high on the BPI-S for both the frequency of behaviors ($\alpha = .88$) and the severity of behaviors ($\alpha = .84$).

Perceived improvement. The Parent Improvement Scale (Child Improvement) (PIS-CI; see appendix D) is an 11-item scale used to evaluate a parent's perception of their child's clinical improvement due to therapy at the time the measure is given (Kazdin & Durbin, 2012). Both broad questions related to improvement (e. g. "How many more skills do you think your child has now compared with before he/she started?"), as well as more specific behavior improvements (e.g. "Does your child react differently to problem situations now compared with when sessions first started?") were included in the survey tool. Responses were given on a Likert scale with options ranging from one to five, with the anchor points (1, 3, and 5) having separate descriptions depending on the question (e.g., 1 = "No new skills", 3 = "Some new skills", and 5 = "A lot of new skills"). Higher scores on this measure indicate a greater perception of improvement in their child's skills and behavior regulation. This measure has been used to assess therapeutic change in clinical samples and discriminate the degree of change between alternative treatments (Kazdin & Durbin, 2012). Our sample also had high internal consistency on the PIS-CI ($\alpha = .95$).

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Parent-therapist alliance. The Therapeutic Alliance Scale for Caregivers and Parents (TASCP; see appendix E) is one of a few different measures used in this field to assess the caregiver-therapist alliance, rated by the parents (Accurso, Hawley, & Garland, 2013). Questions such as, “I look forward to meeting with my child’s therapist” are included in this 12-item scale. Responses were measured on a Likert scale ranging from one (not true) to four (very much true). Five of the statements were reversed so that higher scores indicated a stronger therapeutic alliance between the parent and the therapist. This measure was strongly and significantly related to the therapist-reported caregiver alliance in previous work by Accurso, Hawley and Garland and was positively and significantly related to the total number of sessions attended (2013). There was high internal consistency on the TASCP in our sample ($\alpha = .90$).

Perceived barriers. The Barriers to Treatment Participation Scale (BTPS; see appendix F) was developed to measure barriers and specifically address retention rates for child and adolescent outpatient therapy (Colonna-Pydyn, Gjesfjeld, & Greeno, 2007). Due to the length of the original survey tool, Colonna-Pydyn and colleagues created a shorter version for use in community centers to ease the time demands on the respondents. The shorter version consists of 20 statements such as, “treatment was in conflict with another of my activities (classes, job, friends).” Responses were rated on a Likert scale with a range of 1 (Never a Problem) to 5 (Very Often a Problem). There are two factor loadings that make up this scale; the first factor deals with the client’s experience with the therapist and with treatment and is labeled “treatment expectations” (Colonna-Pydyn, Gjesfjeld, & Greeno, 2007). This factor loading is similar to previous work found in the literature that identifies perceptions and attitudes of treatment as one type of treatment barrier (Andrade et al., 2013; Owens et al., 2002). The second factor loading on the shortened version of the BTPS is made up of items related to unexpected illness, scheduling

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conflicts and other caregiver burdens and was labeled as “external demands” (Colonna-Pydyn, Gjesfjeld, & Greeno, 2007). As before, the previous literature supports this factor loading as part of treatment barriers otherwise known as structural barriers (Andrade et al., 2013; Owens et al., 2002). This measure was validated by a community of caregivers (Colonna-Pydyn, Gjesfjeld, & Greeno, 2007), indicating a good fit for our study. Although this assessment has typically been used as a post-assessment measure to predict premature termination, Kazdin, the author of the scale, has also used the BTPS during treatment to help understand the relation between barriers with quality of daily life, interpersonal relationships, therapeutic alliance, and treatment outcome (Kazdin & McWhinney, 2017). Thus, the BTPS has previously been used in the present tense providing adequate support to do so in our current study. This scale had high internal consistency in our sample ($\alpha = .88$).

Analytic approach

All analyses were carried out in IBM SPSS Statistics 25. Descriptive statistics were computed in order to describe sample characteristics (age, race, relation to child, etc.) as well as provide basic statistical information for each scale. For hypothesis one, a bivariate Pearson correlation was run to determine which variable relationships were significant with each other. In addition, the correlation matrix was used to determine whether the hypotheses correctly predicted the variables that would produce positive and negative relationships with parental stress. For hypothesis two, a stepwise multiple regression was computed to establish which problem behavior variable was most predictive of parental stress. Following that analysis, a hierarchical multiple regression determined which variable(s) would increase prediction of parental stress after accounting for problem behavior. Finally, for hypothesis three, two

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mediation analyses were used to clarify the relationship between parent-therapist alliance and parental stress using Andrew Hayes' PROCESS version 3.3, Model 4 (Hayes, 2013).

Chapter III

Results

Missing data was handled differently depending on the measure. Due to an error on the Qualtrics online survey, participants were not provided one question from the PSI-SF. Missing data from this scale was handled by substituting the average item score for the completed items on the relevant subscale, either Parental Distress, Parent-Child Dysfunction Interaction, or Difficult Child (Abidin, 1995). Similarly, had there been any missing data on the BTPS, average item scores for the completed items on either the attitudinal or external barriers subscale would have been substituted. For the BPI-SF, there were four items in which different participants endorsed a behavior but did not indicate either the frequency or the severity. In these instances, the data for those items was left out of the analyses as mean item score substitution was not appropriate. To accommodate this, a variable was computed for each participant with the total number of problem behaviors they endorsed for their child. For missing data on the TASCP, and PIS-CI scales, mean substitution was implemented, using the average of all the item scores on the measures. Missing data was minimal although four participants were removed from multiple regression and correlation statistics as they did not complete the survey.

The length of time that each participants' child had been in ABA therapy were converted to months. Since the survey question was open ended, and did not suggest a specific unit of measure, participants responded in weeks, months, and years. Three answers could not be

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converted because they did not include a unit of time. Items on the PIS-CI were reversed when necessary (items 2, 5, 7, 8, and 11). A Shapiro-Wilk's test ($p > .05$), visual inspection of the PSI-SF histogram, skewness, and kurtosis all indicated normality for the dependent variable, parental stress. Normality was also tested for all other scales, and despite being visually skewed on their histograms, none of the scales reached the critical threshold of ± 2 for skewness. Average item scores were used within analyses for each scale as opposed to total scale scores although both were computed and reported below.

Descriptive Statistics

Descriptive statistics were computed for all of the scales, both the total scores (Table 1) and the average item scores (Table 2). The item average scores on the Parental Stress Index ranged from 1.28 to 4.23 with a sample mean of 2.81 ($SD = 0.66$). The sum of scores on the PSI-SF, excluding the 7 items from the Defensive Scale, ranged from 37 to 123, with a sample mean score of 81.43 ($SD = 19.15$). A clinically significant stress score (raw score of 90 or above) was reached by 26% of the population. The Defensive Responding scale scores ranged from 7 to 35 with a mean score of 21.21 ($SD = 6.58$). An item average score for the defensive scale had a mean of 3.03 ($SD = 0.94$).

Participants were asked about 30 different behaviors generally considered to be problematic on the BPI-S; the number of behaviors a participant's child engaged in ranged from 0 behaviors to 23 ($M = 10.27$, $SD = 5.88$). Because frequency and severity are not comparable units of measure, both an average item score for frequency ($M = 26.58$, $SD = 16.93$) and severity were calculated for each participant ($M = 6.00$, $SD = 6.00$).

On the perceived improvement scale, the mean total item score for our sample was 42.41 ($SD = 9.68$). Item average scores ranged from 1.64 to 5.00 and had a mean of 3.86 ($SD = 9.68$).

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The sample's average item score on the Parent-therapist alliance scale was 3.67 ($SD = 0.44$); despite having a high average, this measure did not have to be modified as it did not reach the critical threshold of ± 2 for skewness. The total scores for alliance ranged from 29 to 48 ($M = 43.91$, $SD = 5.28$). Our sample scores ranged from never having a problem with any of the 20 barriers (score of 20) to having multiple barriers to treatment (score of 64). For each participant, an average item score was computed, and the Mean of these average item scores is reported for the group ($M = 1.57$, $SD = .55$). The scale is split in half between treatment expectations ($M = 1.41$, $SD = .53$) and external demands ($M = 1.72$, $SD = .72$). An independent samples t test revealed that external demands were significantly higher than treatment expectations ($t(90) = 2.53$, $p = .02$).

Exploratory analyses were conducted to determine whether there were significant differences within the means for each variable (parental stress, problem behaviors, improvement, parent-therapist alliance, and barriers) given the participant's age, age of participant's child, and length of time for ABA services. Although there were a few significant differences, none of the significant findings were linear. Thus, no trends for participant demographics impacted parental stress, problem behavior, improvement, parent-therapist alliance, or barriers.

Correlation Matrix

A correlation matrix was conducted to test our first hypothesis (Table 3). It was expected all the variables to be related in predictable ways, specifically that all three variables of behavioral problems ($r = .48$, $p \leq .001$; $r = .52$, $p \leq .001$; $r = .64$, $p \leq .001$; endorsement, frequency, and severity respectively) and perceived barriers ($r = .44$, $p \leq .001$) would be positively correlated with parental stress, while perceived improvement ($r = -.43$, $p \leq .001$) and therapeutic alliance ($r = -.45$, $p \leq .001$) would be negatively correlated. As expected, all of the

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variables were significantly correlated to parental stress and in the direction predicted. Thus, the first hypothesis was supported. Because the BPI-SF was broken into three outcome variables, frequency average, severity average, and total endorsement count, it was unsurprising that they all were highly correlated with one another. The results of the correlation suggest a strong positive relationship between perceived improvement for their child's behaviors and the parent-therapist alliance ($r = .68, p \leq .001$); parents with stronger alliances with the therapist were more likely to also perceive their child to have more improvement and vice versa. Perceived improvement was also significantly and negatively related to perceived barriers to treatment ($r = -.38, p \leq .001$); lower barriers are associated with parents seeing more improvement from treatment. Lastly, the parent-therapist alliance was significantly negatively related to perceived barriers ($r = -.49, p \leq .001$). Parents with lower barriers were more likely to have higher alliance with the therapist.

Since participants generally reported very high therapist-parent alliance and low perceived barriers, a post hoc analysis was conducted to further analyze the similarities between the two measures. Specifically, a Pearson correlation was run between two items from the BTPS and the entire TASC. Based on clinical judgment, the items "I do not like my therapist" ($r = -.60, p \leq .001$) and "I do not feel the therapist supports me or my efforts" ($r = -.64, p \leq .001$) were chosen as they seemed to best overlap with the alliance construct; both had significant negative correlations with the alliance scale.

Multiple Regression

A hierarchical multiple regression analysis was conducted to examine which factors predict parental stress. It was predicted that all variables would significantly predict parental stress after accounting for problem behaviors. Prior to completing a multiple regression with all

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of the variables, a stepwise multiple regression was conducted to determine which problem behavior outcome variable best predicted parental stress. All three variables, frequency average, severity average, and total endorsement count, were added at the same time. The analysis revealed that 39.1% of parental stress variance was accounted for by the 3 problem behavior variables, $F(1, 46) = 31.14, p \leq .001$. Due to a sample size, smaller than suggested for the number of variables, the adjusted R squared was used to determine variance. Results indicated that the severity score of problem behaviors was the only significant predictor variable ($\beta = 0.64, p \leq .001$). Additionally, the partial correlation between parental stress and severity of problem behavior ($r = .64$) is significantly higher ($p \leq .001$) than the partial correlation between parental stress with frequency of problem behavior ($r = .064$) and total endorsement count ($r = .051$). Because of the high correlation between the three variables, it is unsurprising that only one variable would come out as significant due to a large overlap in variance.

Next the hierarchical multiple regression analysis was conducted. The severity of problem behaviors was added in step one. The standard residual did not reach cut-off (± 3) and neither did Cook's distance (± 1), and therefore the regression was analyzed. Identical to previous analysis, 39.1% of the variance of parental stress was accounted for by the severity of problem behaviors ($\beta = 0.59, p \leq .001$) and significantly predicted parental stress ($F(1, 44) = 29.89, p \leq .001$). The adjusted R squared variable was used to determine variance due to the small sample size. In step two, perceived improvement, parent-therapist alliance, and perceived barrier scores were added to the model. These variables significantly improved the model fit and increased the overall accounted variance of parental stress to 53.0%, ($F(3, 41) = 13.71, p \leq .001$). After accounting for the severity of problem behaviors, the only variable to significantly add to the model was parent-therapist alliance ($\beta = -0.39, p = .015$). The negative standardized

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beta coefficient indicates that the lower parent-therapist alliance is predictive of higher parental stress. Perceived improvement and perceived barriers to treatment did not contribute to a significant portion of the measured variance. Therefore, the second hypothesis was partially supported; although not all of the variables significantly contributed, parent-therapist alliance did aid in the prediction of parental stress.

Mediation Analysis

Our last hypothesis predicted that perceived improvement and perceived barriers to treatment would clarify the relationship between parent-therapist alliance and parental stress. Two separate mediation analyses were conducted using PROCESS v3.3, created by Andrew Hayes, by means of 5,000 bootstrapped samples to analyze these relationships. The first analysis had perceived improvement as the mediator and although the standardized regression coefficient between parent-therapist alliance and perceived improvement was significant (Figure 1) ($b = 1.34, p \leq .001$). However the standardized regression coefficient between improvement and parental stress was not significant ($b = -0.18, p = 0.21$), neither was the standardized regression coefficient between alliance and parental stress, the direct effect ($b = -0.45, p = .112$)., Thus the indirect effect also was not significant and perceived improvement did not mediate the relationship between parent-therapist alliance and parental stress.

Another mediation analysis was conducted to determine if perceived barriers to treatment mediated the relationship between parent-therapist alliance and parental stress. As Figure 2 illustrates, the standardized regression coefficient between parent-therapist alliance and perceived barriers was statistically significant. The standardized regression coefficient between perceived barriers and parental stress was nearing significance but did not reach the cut-off ($b = 0.37, p = 0.05$). Statisticians argue that an indirect effect can still be present despite not having

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significant direct effects, which allows us to continue examining the analyses for the indirect effect (Hayes, 2013). Both the standardized total effect ($b = -0.68$) and the direct effect ($b = -0.46$) were significant ($p \leq .05$). The indirect effect was tested using 5,000 bootstrapped samples and the 95% confidence interval was computed. Since the bootstrapping samples lower and upper limits do not include zero (-0.49 and -0.01 , respectfully), the mediation is statistically significant; the standardized indirect effect was -0.22 . Since the direct effect, otherwise known as the standardized regression coefficient between parent-therapist alliance and parental stress has a smaller coefficient than the total effect, the perceived barriers do partially mediate the relationship between parent-therapist alliance and parental stress; thus the third hypothesis was partially supported.

Chapter IV

Discussion

This study aimed to better understand parental stress for those parents who have a child with ASD and who is currently receiving clinic-based ABA therapy. Specifically, the study examined how the problem behaviors of the participants' children, the parent-therapist alliance, the perceived improvement throughout therapy, and the perceived barriers to therapy influenced and contributed to parental stress. Parental stress scores from this sample are comparable to other findings (e.g., Estes et al., 2009; Giovagnoli et al., 2015; Hsiao, Higgins, Pierce, Whitby & Tandy, 2017). The scores reported in this study are markedly higher than both the sample of parents of typically developing children and of parents of children with ASD in one study (Giovagnoli et al., 2015) and lower than those in another study (Strauss et al., 2012). Our parental stress scores very similar to those reported by researchers Davis and Carter (2008) who discovered that a child's social relatedness, regulatory problems, and externalizing behaviors uniquely contributed to their mothers and fathers' stress. Other research revealed that being a parent of a younger child with ASD, such as preschool age, is associated with higher levels of parental stress (Giovagnoli et al., 2015). This consideration of the child's age might help to explain the higher stress scores in this study because the largest percentage of children were 2-4-

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years-old followed by 5-7-year-olds. High scores for the parental stress scale, which touches on parental distress, is congruent with previous research that found higher rates of depression and anxiety and less overall well-being for parents of a child with ASD (Hayes & Watson, 2013; Hsiao, Higgins, Pierce, Whitby & Tandy, 2017).

Problem Behaviors

The literature consistently reveals that parents of children with autism are more stressed than those with children that are neurotypical or have a different pathology (Estes et al., 2009; Giovagnoli et al., 2015; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Hsiao, Higgins, Pierce, Whitby & Tandy, 2017;). The literature is inconsistent on which variables best predict this stress. The majority of literature has found that the severity of problem behaviors was the largest predictor (Estes et al., 2009), while others have found traits specific to ASD to be more predictive (Giovagnoli et al., 2015). Despite controversy on exactly how much of an impact problem behavior has on stress, the weight of evidence in the literature consistently reveals a connection between problem behaviors and stress. Therefore, we correctly predicted that problem behaviors would account for the most variance within our study's variables when creating a predictive model for stress. Our results are consistent with a large number of studies that also revealed problem behaviors, such as aggression, self-injurious behaviors, and stereotypies are highly associated with, and predictive of, parental stress (i.e., Estes et al., 2009; Giovagnoli et al., 2015).

Specifically, our results were consistent with previous work and also found that the severity of problem behaviors was indicative of parental stress and more predictive than the frequency of behaviors or the number of different problem behaviors a participants' child exhibited. This finding that severity is predictive of parental stress has been also found

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previously (Estes et al., 2009). Perhaps this is not surprising as more severe problem behavior results in greater physical or emotional injury either to the child themselves, related to self-injurious behavior, or to other children, when it is related to aggressive behavior. Intensive healthcare is necessary when these behaviors become too severe, adding further stress as accessing such health care is time-consuming and expensive. Additionally, research has shown that left untreated, aggressive behaviors can become more severe over time, thereby further increasing the overall stress for the parents and the children (Hodgetts, Nicholas, & Zwaigenbaum, 2013). It is logical that with a higher severity of self-injurious, aggressive, and destructive behavior, parents are more alert to their child in hopes of reducing the injury inflicted to themselves or others or the need to repair or replace destroyed or damaged items.

Because stereotyped behavior is best understood by the frequency of the behavior, not severity, the finding that problem behavior severity is most predictive of stress implies that all stereotypical behaviors are not as important as aggressive and self-injurious behaviors when trying to understand the stress of parenting the ASD child. Such a conclusion is consistent with the findings of Giovagnoli and colleagues (2015) who found that aggressive behavior was the most predictive problem behavior for parental stress on the PSI. However, it should be noted that in our study the three variables of problem behaviors (severity of behaviors, frequency of behaviors, and number of endorsed behaviors) are highly interrelated, and thus all significantly correlated with parental stress levels. Previous literature reveals that a bi-directional relationship can occur; problem behaviors predict high parenting stress, which disrupts parenting behavior, which can then lead to a further increase in problem behaviors (Estes et al., 2009; Hwang, Kearny, Klieve, Lang, & Roberts, 2015). If correct, the described bi-directional relationship

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would provide further evidence for the high association between stress and problem behaviors, as reported by others (Estes et al., 2009; Hwang, Kearny, Klieve, Lang, & Roberts, 2015).

Perceived Improvement

As all of the participants' children in this study were receiving clinic-based ABA therapy, this study provides an interesting and specific outlook on how perceived improvement within this therapy type contributes to parental stress. The hypothesis that improvement would be negatively associated with parental stress was correct. Parents that perceived that their child improved through their ABA therapy were more likely to report less stress. Specific to ABA, two studies found improvement occurring following in-home ABA to be related to lowering parental stress (Birnbauer & Leach, 1993; McPhilemy & Dillenburger, 2013). Slade and colleagues found that reducing the number of patient-rated unmet needs was associated with higher quality of life (2005). The increased coping skills learned through ABA, such as their child reacting differently to problem situations, implies a 'met' need for parents, which is associated with lower stress which could be related to a perceived higher quality of life. Slade and colleagues also found that the reduction of patient unmet needs was predictive of quality of life (Slade, Leese, Cahill, Thornicroft, & Kuipers, 2005). Our results suggest that the perceived improvement of applying ABA methods does not predict lower parental stress significantly, thus differing from Slade and colleagues' findings. It should be noted that that quality of life and stress are separate constructs however, literature on family quality of life in families with a child with ASD has shown a strong negative correlation with parental stress (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017). Additionally, parental stress was found to significantly predict family quality of life (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017). The measures used for perceived improvement in a child's behavior is not specific to ASD problem behaviors or ABA treatment

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goals; this lack of specificity may explain why this measure was not helpful for predicting parental stress in our study.

Our results indicate that high scores on perceived improvement were associated with high scores for parent-therapist alliance and vice versa. Many studies have found a relationship between alliance and treatment outcomes, and despite that perceived improvement was a variable assessed during treatment and not afterwards, it is unsurprising that we also found a relationship. More specifically, research on child mental health treatment has found that a strong alliance between professionals, the child clients, and their parents is predictive of better treatment outcomes (de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017; Green, 2006; Kazdin & McWhinney, 2018; Shirk, Karver, & Brown, 2011). Multiple studies also found that that high parental stress reduced the effectiveness of early intervention programs which in turn impaired clinical improvement (e.g., Davis & Carter, 2008; Giovagnoli et al., 2015; Robbins, Dunlap, & Plenis, 1991). These findings also provide evidence to explain the high correlation between patient, parent and therapist alliance with stress. Within the prediction model for parental stress, alliance may be intricately related to the construct of improvement if the measures are too similar or if parents have a difficult time distinguishing their satisfaction with the therapist apart from their child's improvement.

Parent-therapist Alliance

The findings from this study reveal very strong positive feelings of parent-therapist alliance. High alliance scores could be a result of participants' social desirability. In other words, respondents might distort their actual feelings concerning their child's therapist to reflect a life of greater social norm and to maintain a socially favorable self-presentation to their family and friends (Krumpal, 2013). Alternatively, individuals could be experiencing cognitive dissonance.

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For example, a parent may improve their feelings toward the therapist in order to resolve the discomfort they may feel for spending a significant amount of time and money for such therapy (Encyclopaedia Britannica, 2019). In addition, it is also plausible that participants who already had a strong alliance with their child's therapist were more likely to complete the survey.

Because some of the therapists were the ones to alert parents to the study through email, it is reasonable to consider that at least some participants were more inclined to participate in a study that their therapist promoted.

Additionally, our results indicated that parent-therapist alliance is important to understanding stress experienced by parents of ASD children. In this study, alliance is significantly and negatively associated with parental stress. Parents that reported a strong relationship with their child's therapist were more likely to report lower stress. Although the literature is mixed on the importance of parent-professional alliance for child-related treatment, our findings were compatible with others which found that stronger alliance between the parent and professional predicted better youth therapy outcomes and lower drop-out rates (e.g., de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017; Kazdin & McWhinney, 2018). Researchers have found that teachers of children with ASD can cultivate positive relationships with parents through frequent and honest communication regarding the child's progress and problems (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017). Using data to assess a child's performance and focusing on possible solutions to problem behaviors rather than blaming parents is also beneficial to the parent-teacher relationship (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017). Though these findings were directed toward teachers working with children with ASD, they are very applicable to ABA therapists as they also use data collection to help with behavior change and meet with parents to discuss their child's progress.

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Our results also reveal that after accounting for problem behaviors, parent-therapist alliance significantly adds to the model for predicting parental stress. This finding demonstrates the importance of alliance with parents for clinic-based ABA therapy. The questionnaire used to measure alliance has many statements pertaining to time spent with the therapist and working on problems. These statements are particularly important for this therapy and population because reducing problem behaviors is one of the main goals for children with ASD. Literature has shown that strong and trusting alliances with professionals also led to better maternal functioning; a large majority of the respondents were mothers in this study so improved maternal function might be operational herein (Davis, 2007). Our results, consistent with previous such studies, stresses the importance of parent-professional alliance in order to reduce parental stress, to improve therapy outcomes, and to reduce drop-out rates.

Perceived Barriers

Our participants endorsed very few barriers to treatment. In this study, structural barriers such as competing responsibilities for time were reported to be significantly higher than attitudinal barriers, such as treatment expectations not being met. Previous research revealed that drop-out rates were predominantly related to attitudinal barriers (Andrade et al., 2013). Because our sample was actively engaged in ABA therapy and those who had dropped out were not a part of our sample may explain why structural barriers are mentioned more often. Ultimately, the lower reporting of perceived barriers could also be a result of the fact that in this study the average length of time families participated in ABA therapy was nearly 2 years. To maintain therapy for that long, they likely had to make adjustments in their routine to attend therapy regularly and were perhaps satisfied enough with ABA therapy to stay engaged as long as they

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have. The barriers might not be as significant for parents who have already overcome obstacles to start and to maintain treatment for their child.

Despite low scores for perceived barriers, the scores still played a role in understanding parental stress as our results suggest a positive relationship between barriers and stress. This association between parental stress and barriers is consistent with the literature for parents of children receiving behavioral therapy for oppositional, aggressive, and antisocial behaviors (Kazdin & McWhinney, 2018; Kazdin, Holland, Crowley, & Breton, 1997). It is encouraging that other research indicates that fewer perceived barriers during treatment were associated with greater therapeutic outcomes at the end of treatment (Kazdin & McWhinney, 2018); it is possible that because this sample reported a low number of barriers, their children will have more positive therapeutic outcomes. As stated previously, our perceived improvement scale is an evaluation of how much therapeutic change has occurred at this point of time in the child's treatment. Thus, it is unsurprising that our results reveal a negative relationship between perceived barriers and improvement; that is, fewer barriers present is related to higher perceived improvement.

Perceived barriers also had a strong, negative relationship with parent-therapist alliance. Half of the barrier scale, BTPS, is related to by attitudinal barriers. Two of the attitudinal barrier statements are "I do not like my therapist" and "I do not feel the therapist supports me or my efforts" (Kazdin, Holland, Crowley, & Breton, 1997). Post hoc analysis demonstrated a strong significantly relationship between the two items on the barriers scale with the alliance scale. Previous literature shows that higher quality of life scores and stronger interpersonal relationships with friends, partners, and family were predictive of parent-therapist alliance (Kazdin & McWhinney, 2018) as well as parent engagement in therapy and parent hostility (Green, 2006). Clearly extraneous factors impact the parent-therapist alliance and it seems likely

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that one of those factors are the barriers parents have to go through to begin and maintain ABA treatment for their child. It is possible that other life stressors, assessed for on the BTPS by statements such as “My job gets in the way of coming to a session”, negatively impacts the relationship with the therapist as well (Kazdin, Holland, Crowley, & Breton, 1997).

Additionally, based on our analysis, perceived barriers help explain the relationship between parent-therapist alliance and parental stress. This means that even parents with strong relationships with their therapist are affected negatively by barriers which impact their experience of stress. The relationship of alliance and stress is better explained when barriers are added to mediate the relationship. Our results that revealed a direct effect between parent-therapist alliance and parental stress were contrary to a study that examined the parent-teacher relationship in children with ASD in school settings (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017). These researchers also examined a parent-professional alliance to determine whether the alliance impacted parental stress and the families’ quality of life. Instead of a direct impact on parental stress, the parent-teacher alliance had an indirect effect through the perceived family quality of life (Hsaio, Higgins, Pierce, Whitby, & Tandy, 2017). Although seemingly different results, the quality of life scale used included questions about family interaction and parenting, while their stress measurement scale did not. Since our stress scale also included parent-child interactions and parenting, there may be an overlap in these questionnaires indicating similarities between the studies. Either way, both this study and Hsaio’s study suggest that when parent-professional alliances are supportive and collaborative, in samples of parents of child with ASD, it is beneficial for the parents and their whole family system.

Limitations

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Several limitations of this study must be noted. First, convenience sampling was implemented rather than the more widely accepted random sampling. Clinics were chosen based on professional connections and geographic locations. Additionally, some parents offered to pass on the study information to other parents they know which could have been somewhat of a snowball effect for recruitment as well. This type of sampling clearly is prone to biases. For example, ABA clinics have differences in their operations such as time for drop-off and pick-up, the number of meetings with their therapist, and so on, which could impact our results because we recruited from only five clinics. There is the possibility that recruiting from treatment centers within a 2-hour radius might have socioeconomic implications.

The most significant limitation of this study is the sample size. Smaller sample sizes often do not represent the population well; in this case, our 50 participants could be skewed in some unclear way and not represent parents of children with ASD receiving clinic-based ABA services. One way to accommodate this perceived potential short-coming would be to assess covariates that could impact the sample's results. Assessing more demographic information, (i.e., parent education level, driving distance to their ABA clinic, time spent on the waitlist), could have provided an indication of sample characteristics and the possible skewing of results driven by one or more of the covariates. One covariate that would provide more information on the sample is social desirability, which was mentioned previously. Our sample could have been skewed as having higher social desirability resulting in high item score averages for the parent-therapist alliance questionnaire and the perceived improvement questionnaire. Although statistical power is a concern with small samples, the study did have many significant findings.

Finally, our study was cross-sectional, meaning all factors were measured simultaneously. Thus, the results cannot be causal but instead are correlational in nature. Despite

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a prediction and mediation model, it is difficult to determine which variable predicts the other. It is possible that the relationships occur in the opposite direction than described (i.e., lower parental stress is predictive of high parent-therapist alliance).

Future research

Future research is needed to corroborate our findings. Specifically, a sample size of at least 108 parents of children with ASD receiving clinic-based ABA therapy would be more ideal for both the multiple regression and mediation analyses. By increasing the sample size, there would be less room for biases. This study suggests that barriers to treatment not only is associated with higher parental stress but also mediates the already strong relationship between parent-therapist alliance and parental stress. Future research on parents of children receiving clinic-based ABA therapy could provide an open-ended question where parents could list what barriers impact them most. In addition, future research could investigate further demographic covariates, such as parental education level and socioeconomic status. Barriers in relation to other covariates might provide further information that therapists and social workers could use to address a variety of difficulties parents could be experiencing. Finally, since parent-therapist alliance was so indicative of lower parental stress, this factor should be more fully explored by determining which parts of interactions with professionals are most beneficial to parents.

Implications

About 1 in 59 children have been identified with ASD (CDC, 2010), which some experts believe is an underestimate of the actual prevalence for ASD (Christensen, 2019). The literature has shown time and again that parents of children with ASD have significantly higher rates of stress than parents of typically developing children or children with different pathologies. Our study specifically examined this parental stress by focusing on four contributing factors: problem

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behaviors, perceived improvement, parent-therapist alliance, and perceived barriers to treatment. Our results indicate that the parent-therapist alliance, after problem behaviors, plays a significant role in reducing parental stress. Thus, these results are extremely useful for clinic-based ABA therapists. Establishing a supportive and honest relationship will not only relieve stress for parents, but it may imply that parents will be more open to realizing improvement in their child through therapy. Additionally, reducing parental stress has been shown to improve the problem behaviors with which a child patient presents at the beginning of therapy. As clinics become more aware of the hurdles their parents face to receive services, they could implement changes within their systems to better serve their child patients and their parents. For example, implementing a bus route to pick up clients that would not otherwise be able to attend therapy. It is imperative for reasons of cost and effectiveness of treatment that the healthcare system reacts to the growing prevalence of ASD by delivering services to families that are accessible and efficient. By addressing the critical nature of parental stress of ASD children, our study sheds light on what needs to be addressed to reduce drop-out rates in ASD therapy and thereby improve the function and success of the ASD child and their families.

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Tables

Table 1.
Descriptive Statistics for Measure Average Item Scores (N = 46)

| Measure | Minimum | Maximum | Mean | Standard Deviation |
|-----------------------------------|----------------|----------------|-------------|---------------------------|
| Parental Stress | 1.28 | 4.23 | 2.81 | .66 |
| Problem Bx: Frequency | 0 | 2.43 | .88 | .56 |
| Problem Bx: Severity Perceived | 0 | 1.33 | .33 | .33 |
| Improvement | 1.64 | 5.00 | 3.86 | .88 |
| Parent-Therapist Alliance | 2.42 | 4.00 | 3.67 | .44 |
| Perceived Barriers | 1 | 3.20 | 1.57 | .55 |

Note. Problem behavior endorsement count is not included as it considered a total amount and not an average item amount. There was a minimum of 0 behaviors endorsed and a maximum of 23 behaviors endorsed ($M = 10.27$).
 Problem Bx = Problem Behavior

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Table 2.
Correlation between Parental Stress and Predictor Variables (N = 46)

| Measure | 1 | 2 | 3 | 4 | 5 | 6 |
|--------------------------------|--------|-------|-------|-------|--------|--------|
| 1. Parental Stress | — | | | | | |
| 2. Problem Bx's Endorsement | .48** | — | | | | |
| 3. Problem Bx's Frequency | .52** | .95** | — | | | |
| 4. Problem Bx's Severity | .64** | .87** | .85** | — | | |
| 5. Improvement | -.43** | -.22 | -.23 | -.32* | — | |
| 6. Alliance | -.45** | -.02 | .01 | -.08 | .68** | — |
| 7. Barriers | .44** | .27 | .20 | .28 | -.38** | -.49** |

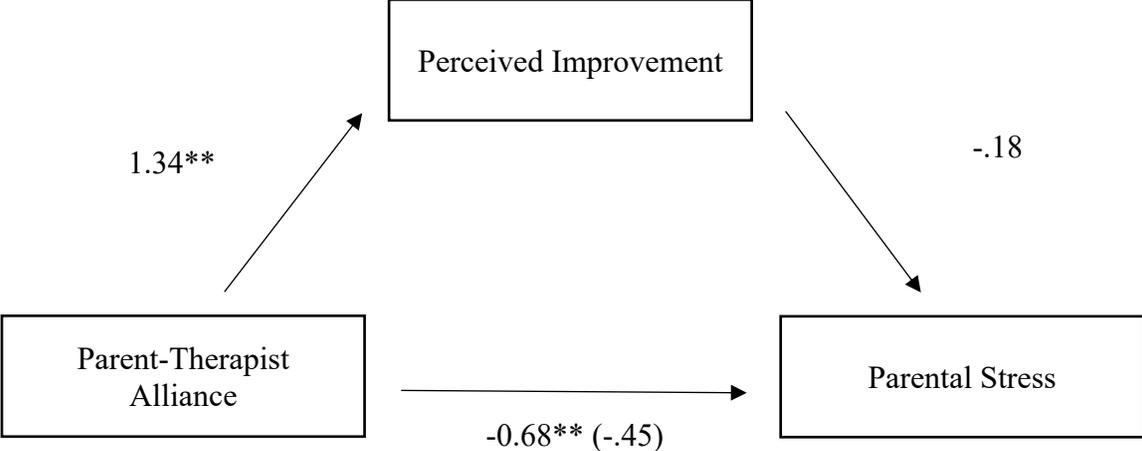
Note. Problem Bx = Problem Behavior

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Figures

Figure 1.
Mediation Model of Parent-Therapist Alliance and Perceived Improvement to Parental Stress

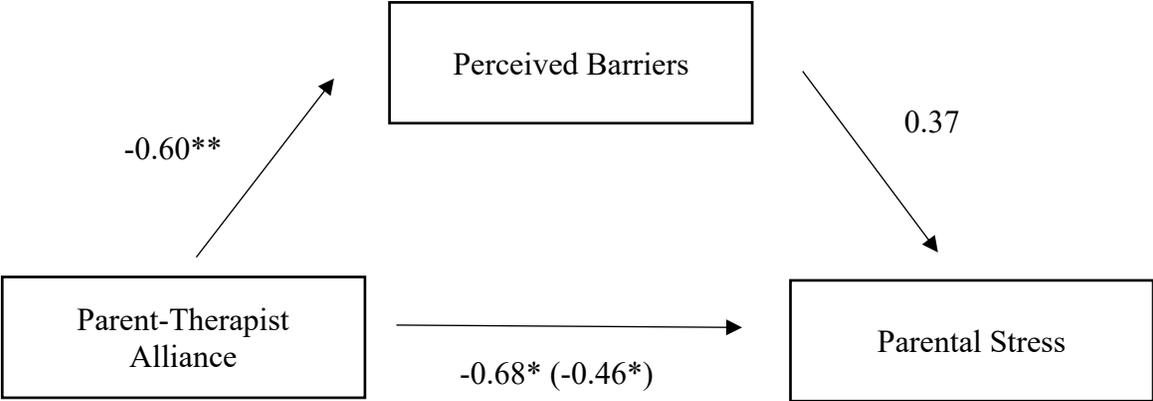


Standardized regression coefficients for the relationship between parent-therapist alliance and parental stress as mediated by perceived improvement. The standardized coefficient between parent-therapist alliance and parental stress, controlling for perceived barriers, is in the parenthesis.

** Standardized Regression Coefficient is significant at the 0.01 level.

* Standardized Regression Coefficient is significant at the 0.05 level.

Figure 2.
Mediation Model of Parent-Therapist Alliance and Perceived Barriers to Parental Stress



Standardized regression coefficients for the relationship between parent-therapist alliance and parental stress as mediated by perceived barriers. The standardized coefficient between parent-therapist alliance and parental stress, controlling for perceived barriers, is in the parenthesis.

** Standardized Regression Coefficient is significant at the 0.01 level.

* Standardized Regression Coefficient is significant at the 0.05 level

Appendix A: Demographic Variables

Please circle one.

What is your age?

- 18-22 23-27 28-32 33-37 38-42 43-47 48+

What is your gender?

- Male Female

What is your child’s gender?

- Male Female

What is your race/ethnicity? (Circle all that apply)

- White
- Black or African American
- Non-White Hispanic
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Island
- Middle Eastern/North African
- Other

What is your child’s race/ethnicity? (Circle all that apply)

- White
- Black or African American
- Non-White Hispanic
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Island
- Middle Eastern/North African
- Other

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What is your relationship to your child?

Mother Grandmother Other primary caregiver:

Father Grandfather

What is your child's age?

2-4 5-7 8-10 11-13 14-16 17-18

How often does your child receive services?

weekly monthly

biweekly other: _____ times per week

Circle all that apply.

Which services does your child receive currently?

One-on-one ABA therapy Early Intensive Behavioral Intervention (for ? to ?)

Social Skills Group Skill Building Clinic (toileting, picky eating, sleep)

Parent Child Interaction Therapy Other:

Complete the following.

How long has it been since your child started treatment for autism?

Appendix B: The Parental Stress Index – Short Form (PSI-SF)



Instructions

This questionnaire contains 36 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the SA if you strongly agree with the statement.

Circle the A if you agree with the statement.

Circle the NS if you are not sure.

Circle the D if you disagree with the statement.

Circle the SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA A NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Circle only one response for each statement, and respond to all statements. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS X SD

| | SA = Strongly Agree | A = Agree | NS = Not Sure | D = Disagree | SD = Strongly Disagree |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------|-----------|---------------|--------------|------------------------|
| 1. I often have the feeling that I cannot handle things very well. | SA | A | NS | D | SD |
| 2. I find myself giving up more of my life to meet my children's needs than I ever expected. | SA | A | NS | D | SD |
| 3. I feel trapped by my responsibilities as a parent. | SA | A | NS | D | SD |
| 4. Since having this child, I have been unable to do new and different things. | SA | A | NS | D | SD |
| 5. Since having a child, I feel that I am almost never able to do things that I like to do. | SA | A | NS | D | SD |
| 6. I am unhappy with the last purchase of clothing I made for myself. | SA | A | NS | D | SD |
| 7. There are quite a few things that bother me about my life. | SA | A | NS | D | SD |
| 8. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend). | SA | A | NS | D | SD |
| 9. I feel alone and without friends. | SA | A | NS | D | SD |
| 10. When I go to a party, I usually expect not to enjoy myself. | SA | A | NS | D | SD |
| 11. I am not as interested in people as I used to be. | SA | A | NS | D | SD |
| 12. I don't enjoy things as I used to. | SA | A | NS | D | SD |
| 13. My child rarely does things for me that make me feel good. | SA | A | NS | D | SD |
| 14. Sometimes I feel my child doesn't like me and doesn't want to be close to me. | SA | A | NS | D | SD |
| 15. My child smiles at me much less than I expected. | SA | A | NS | D | SD |
| 16. When I do things for my child, I get the feeling that my efforts are not appreciated very much. | SA | A | NS | D | SD |
| 17. When playing, my child doesn't often giggle or laugh. | SA | A | NS | D | SD |
| 18. My child doesn't seem to learn as quickly as most children. | SA | A | NS | D | SD |
| 19. My child doesn't seem to smile as much as most children. | SA | A | NS | D | SD |
| 20. My child is not able to do as much as I expected. | SA | A | NS | D | SD |
| 21. It takes a long time and it is very hard for my child to get used to new things. | SA | A | NS | D | SD |
| For the next statement, choose your response from the choices "1" to "5" below. | | | | | |
| 22. I feel that I am: | | | | | |
| 1. not very good at being a parent | 1 | 2 | 3 | 4 | 5 |
| 2. a person who has some trouble being a parent | | | | | |
| 23. I expected to have closer and warmer feelings for my child than I do and this bothers me. | SA | A | NS | D | SD |
| 24. Sometimes my child does things that bother me just to be mean. | SA | A | NS | D | SD |
| 25. My child seems to cry or fuss more often than most children. | SA | A | NS | D | SD |
| 26. My child generally wakes up in a bad mood. | SA | A | NS | D | SD |
| 27. I feel that my child is very moody and easily upset. | SA | A | NS | D | SD |
| 28. My child does a few things which bother me a great deal. | SA | A | NS | D | SD |
| 29. My child reacts very strongly when something happens that my child doesn't like. | SA | A | NS | D | SD |
| 30. My child gets upset easily over the smallest thing. | SA | A | NS | D | SD |
| 31. My child's sleeping or eating schedule was much harder to establish than I expected. | SA | A | NS | D | SD |
| For the next statement, choose your response from the choices "1" to "5" below. | | | | | |
| 32. I have found that getting my child to do something or stop doing something is: | 1 | 2 | 3 | 4 | 5 |
| 1. much harder than I expected | | | | | |
| 2. somewhat harder than I expected | | | | | |
| 3. about as hard as I expected | | | | | |
| 4. somewhat easier than I expected | | | | | |
| 5. much easier than I expected | | | | | |
| For the next statement, choose your response from the choices "10+" to "1-3." | | | | | |
| 33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. | 10+ | 8-9 | 6-7 | 4-5 | 1-3 |
| 34. There are some things my child does that really bother me a lot. | SA | A | NS | D | SD |
| 35. My child turned out to be more of a problem than I had expected. | SA | A | NS | D | SD |
| 36. My child makes more demands on me than most children. | SA | A | NS | D | SD |

Appendix C: The Behavior Problems Inventory – Short Form (BPI-S)

| | | Yes No | | SELF-INJURIOUS BEHAVIOR | | | | Severity of the Problem | | | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|--------------------------|--------------------------|---------------------------------|--------|-------|--------|------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|--|
| | | | | Average Frequency of Occurrence | | | | Mild | Moderate | Severe | |
| | | | | Monthly | Weekly | Daily | Hourly | Behavior occurs but does not inflict significant damage (e.g., reddening of the skin, very light bruising) | Behavior inflicts moderate amount of damage (e.g., moderate bruising, scratching through the skin) | Behavior inflicts moderate to severe damage (e.g., biting through skin), minor or major medical help needed | |
| <p><i>Self-injurious behavior (SIB) causes damage to the person's own body and occurs repeatedly in the same way over and over again.</i></p> <p>Have you seen your child participate in these activities in the last 6 months?</p> | | | | | | | | | | | |
| 1 | Self-biting | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | |
| 2 | Head hitting | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | |
| 3 | Body hitting (except for the head) with own hand or with any other body part | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | |
| 4 | Self-scratching | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | |
| 5 | Pica (ingesting non-food items) | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | |
| 6 | Inserting objects in nose, ears, anus, etc. | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | | |

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| | | | | | | | | | |
|---|--------------------------------------------|---------------------------------------------------|---|---|---|---|---|---|---|
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 7 | Hair pulling (tearing out patches of hair) | <input type="checkbox"/> <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 8 | Teeth grinding (evidence of ground teeth) | <input type="checkbox"/> <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

| | | Yes No | | Average Frequency of Occurrence | | | | Severity of the Problem | | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------|--------------------------|--------------------------|---------------------------------|--------|-------|--------|-------------------------|----------|--------|
| | | | | Monthly | Weekly | Daily | Hourly | Mild | Moderate | Severe |
| <p><i>Aggressive or destructive behaviors are deliberate overt attacks directed towards other individuals or property.</i></p> <p>Have you seen your child participate in these activities in the last 6 months?</p> | | | | | | | | | | |
| 9 | Hitting others | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 10 | Kicking others | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 11 | Pushing others | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 12 | Biting others | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 13 | Grabbing and pulling others | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |

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| | | | | | | | | | |
|----|--------------------------------------------------------------------------|---------------------------------------------------|---|---|---|---|---|---|---|
| 14 | Scratching others | | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 15 | Pinching others | <input type="checkbox"/> <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 16 | Verbally abusive with others | <input type="checkbox"/> <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 17 | Destroying things (e.g., rips clothes, throws chairs, smashes tables) | <input type="checkbox"/> <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 18 | Bullying - being mean or cruel (e.g., grabbing toys or food from others) | <input type="checkbox"/> <input type="checkbox"/> | | | | | | | |
| | If yes, how often? And how severe? | | 1 | 2 | 3 | 4 | 1 | 2 | 3 |

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STEREOTYPED BEHAVIOR

| <p><i>Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again. However, they do NOT cause physical damage.</i></p> <p>Have you seen your child participate in these activities in the last 6 months?</p> | | <p>Yes. No</p> | | <p>Average Frequency of Occurrence</p> | | | |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------|--------------------------|--------------------------|----------------------------------------|--------|-------|--------|
| | | | | Monthly | Weekly | Daily | Hourly |
| 19 | Rocking, Repetitive body movements | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 20 | Sniffing objects, own body | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 21 | Waving or shaking arms | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 22 | Manipulating (e.g., twirling, spinning) objects | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 23 | Repetitive hand and/or finger movements | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 24 | Yelling and screaming | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 25 | Pacing, jumping, bouncing, running | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 26 | Rubbing self | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 27 | Gazing at hands or objects | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |
| 28 | Bizarre body postures | <input type="checkbox"/> | <input type="checkbox"/> | | | | |
| | If yes, how often? | | | 1 | 2 | 3 | 4 |

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| | |
|----|--------------------|
| 29 | Clapping hands |
| | If yes, how often? |
| 30 | Grimacing |
| | If yes, how often? |

| |
|---------------------------------------------------|
| <input type="checkbox"/> <input type="checkbox"/> |
| <input type="checkbox"/> <input type="checkbox"/> |

| | | | |
|---|---|---|---|
| | | | |
| 1 | 2 | 3 | 4 |
| | | | |
| 1 | 2 | 3 | 4 |

Appendix D: The Parent Improvement Scale (Child Improvement (PIS-CI))

The purpose of this scale is to obtain your overall evaluation of your child's therapy. Your answers will be confidential and not shown to your child or therapist. Please complete this rating scale for the child by circling the number which corresponds to your rating

1. Please rate how much you think your child learned from the sessions.

| | | | | |
|-----------------|---|--------------|---|---------------|
| 1 | 2 | 3 | 4 | 5 |
| Learned nothing | | Learned some | | Learned a lot |

2. How many more skills do you think your child has now compared with before he/she started?

| | | | | |
|---------------|---|-----------------|---|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| No new skills | | Some new skills | | A lot of new skills |

3. How much did he or she learn about controlling his/her behavior?

| | | | | |
|-----------------|---|--------------|---|---------------|
| 1 | 2 | 3 | 4 | 5 |
| Learned nothing | | Learned some | | Learned a lot |

4. Please rate how much new information you now have about how to deal with children.

| | | | | |
|-----------------|---|--------------|---|---------------|
| 1 | 2 | 3 | 4 | 5 |
| Learned nothing | | Learned some | | Learned a lot |

5. Please rate how much you feel your child can use and apply what was learned.

| | | | | |
|--------------------------------|---|------------------------------|---|--------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Can almost never use, or apply | | Use them about half the time | | Can use, apply very much |

6. To what extent are you able to use what you learned about your child's therapy with your child?

| | | | | |
|------------------------|---|----------------------|---|------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all able to use | | Somewhat able to use | | Very able to use |

7. Has what your child learned changed the way you react to your child?

| | | | | |
|------------|---|-------------|---|----------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | | Some change | | Changed a great deal |

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8. Does your child react differently to problem situations now compared with when sessions first started?

- | | | | | |
|----|---|----------|---|------------------|
| 1 | 2 | 3 | 4 | 5 |
| No | | Somewhat | | Very differently |

9. Is your child now more able to act appropriately?

- | | | | | |
|----|---|--------------------|---|-----------|
| 1 | 2 | 3 | 4 | 5 |
| No | | Somewhat more able | | Very able |

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Appendix E: Parent-Therapist Alliance for Caregivers and Parents (TASCP)

These 12 questions will ask you questions pertaining to your relationship with your child's therapist.

| Circle one response for each statement | Not True | | | Very Much True |
|-------------------------------------------------------------------------------------|----------|---|---|----------------|
| I like spending time with my child's therapist. | 1 | 2 | 3 | 4 |
| I find it hard to work with my child's therapist on solving problems in our lives. | 1 | 2 | 3 | 4 |
| I feel like my child's therapist is on my side and tries to help me. | 1 | 2 | 3 | 4 |
| I work with my child's therapist on solving our problems. | 1 | 2 | 3 | 4 |
| When I'm with my child's therapist, I want the sessions to end quickly. | 1 | 2 | 3 | 4 |
| I look forward to meeting with my child's therapist. | 1 | 2 | 3 | 4 |
| I feel like my child's therapist spends too much time working on our problems. | 1 | 2 | 3 | 4 |
| I'd rather do other things than meet with my child's therapist. | 1 | 2 | 3 | 4 |
| I use my time with my child's therapist to make changes in our lives. | 1 | 2 | 3 | 4 |
| I like my child's therapist. | 1 | 2 | 3 | 4 |
| I would rather not work on our problems with my child's therapist. | 1 | 2 | 3 | 4 |
| I think my child's therapist and I work well together on dealing with our problems. | 1 | 2 | 3 | 4 |

Appendix F: The Barriers to Treatment Participation Scale (BTPS)

This survey will ask you about obstacles that make it difficult for you and your child to participate in treatment.

Circle ONE answer for each statement

| | Totally Agree | | Neutral | | Totally Disagree |
|------------------------------------------------------------------------------------|---------------|---|---------|---|------------------|
| 1. Scheduling of appointment times for treatment was difficult | 1 | 2 | 3 | 4 | 5 |
| 2. Treatment lasted too long (too many weeks) | 1 | 2 | 3 | 4 | 5 |
| 3. Treatment was in conflict with another of my activities (classes, job, friends) | 1 | 2 | 3 | 4 | 5 |
| 4. I did not like the therapist | 1 | 2 | 3 | 4 | 5 |
| 5. Treatment was not what I expected | 1 | 2 | 3 | 4 | 5 |
| 6. Information in the session seemed confusing | 1 | 2 | 3 | 4 | 5 |
| 7. My child had trouble understanding treatment | 1 | 2 | 3 | 4 | 5 |
| 8. Crises at home made it hard for me to get to a session | 1 | 2 | 3 | 4 | 5 |
| 9. I felt treatment did not focus on my life and problems | 1 | 2 | 3 | 4 | 5 |
| 10. The therapist did not seem confident that treatment would work for my child | 1 | 2 | 3 | 4 | 5 |
| 11. The therapist did not seem confident in my ability to carry out programs | 1 | 2 | 3 | 4 | 5 |
| 12. Treatment did not seem to be working | 1 | 2 | 3 | 4 | 5 |
| 13. I did not feel that I had enough to say about what goes on in treatment | 1 | 2 | 3 | 4 | 5 |
| 14. I did not feel the therapist supports me or my efforts | 1 | 2 | 3 | 4 | 5 |
| 15. There was always someone sick in my home | 1 | 2 | 3 | 4 | 5 |

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| | | | | | |
|---------------------------------------------------------------------------------------|---|---|---|---|---|
| 16. Getting a baby-sitter so I could come to the sessions was difficult | 1 | 2 | 3 | 4 | 5 |
| 17. I was too tired after work to come to a session | 1 | 2 | 3 | 4 | 5 |
| 18. My job got in the way of coming to a session | 1 | 2 | 3 | 4 | 5 |
| 19. Treatment took time away from spending time with my children | 1 | 2 | 3 | 4 | 5 |
| 20. I had trouble with other children at home which made it hard to come to treatment | 1 | 2 | 3 | 4 | 5 |

Appendix G: Informed Consent

Consent to Participate in a Research Study
TREATMENT RELATED STRESS IN PARENTS OF CHILDREN WITH AUTISM

You are invited to participate in a research study about caregivers' stress related to their child's services (i.e. ABA therapy, group therapy, etc.) for autism spectrum disorder.

If you agree to be part of the research study, you will be asked to complete a demographic form, which will also have questions about child services (i.e. type of services, duration, frequency) as well as five questionnaires regarding your sense of alliance with your child's therapist, your child's behavior, your child's improvement, and your stress.

Benefits of the research: There are no direct benefits from participation in this study.

Risks and discomforts: There is minimal risk associated with participation in this study. However, personal discomfort may arise from answering questions regarding your experiences of stress.

Time: This study should take around 20-30 minutes to complete

Compensation: \$10 gift card

Instructions: Please complete the demographic form and four questionnaires and place in them in the pre-addressed manila envelope. Next, complete the slip of paper located in the standard envelope with your name and mailing address. Keep the envelopes separate when mailing them back and do **not** place the standard envelope inside of the manila envelope. This ensures that your name and mailing address are never connected to your survey responses which maintains confidentiality.

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to answer any survey questions for any reason. Your responses will be kept completely confidential.

If you have questions about this research study, you may contact:

Christin DeWit
Principle Investigator
cdewit@umich.edu

Dr. Nancy Wrobel
Faculty Advisor
nwrobel@umich.edu

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The University of Michigan Health Sciences and Behavioral Sciences Board has reviewed this study and determined that it is exempt from IRB oversight.

Please check the following:

I am 18 years old or older

I acknowledge the information provided above and agree to do the study