THE ROLE OF INDIVIDUAL AND FAMILIAL FACTORS ON PARENTAL ADHERENCE TO TREATMENT RECOMMENDATIONS FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

A Thesis

Submitted to the Graduate School of the University of Notre Dame in Partial Fulfillment of the Requirements for the Degree of Master of Arts

by

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Parents are an integral component of treatment for individuals with autism spectrum disorders (ASD) as they provide continuity, maintenance, and generalization of learned skills. It is crucial that parents adhere to prescribed recommendations to optimize treatment effectiveness. However, it remains unclear how individual or familial contextual factors influence parental adherence. Two hundred and two caregivers of individuals with ASD completed online questionnaires. Questionnaires screened for accuracy of diagnosis, measured current ASD symptoms, adaptive functioning, and parental adherence to treatment recommendations. These data showed adaptive functioning was predictive of parent adherence to medical treatment recommendations over and above what was accounted for by parent-reported diagnoses. Contrary to our predictions, we did not find a relationship between ASD symptom severity or our predicted familial and contextual factors and adherence. When prescribing treatment recommendations, professionals need to be cognizant of how individual and familial contextual factors influence parental adherence.
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INTRODUCTION

I. Background

Autism is a neurodevelopmental disorder characterized by impairment in social interactions and communication, and preoccupation in repetitive behaviors and/or interests (American Psychiatric Association, 2000). Autism spectrum disorders (ASD) is a broader term used to refer to a number of categorical diagnoses, including Autistic Disorder, Asperger syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), that all share a core deficit in social communication and are thought to represent degrees of the same disorder (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Despite a rising prevalence in the number of individuals diagnosed with ASD (Kogan et al., 2009), there is a still a lack of research on the efficacy of treatments (Vismara & Rogers, 2010) and components of treatment effectiveness, such as parental adherence to treatment plans.

Parents are an integral component of treatment for individuals with ASD. They are vital in the effectiveness of prescribed treatments as they provide continuity in treatment from session to session and maintenance of skills after the treatment has been completed (Lovaas, Koegel, Simmons, & Stevens-Long, 1973; Schopler & Reichler, 1971; Vismara & Rogers, 2010). Moreover, parents aid in the generalization of learned skills from the clinical setting to the home setting (Dunlap, 1999; Koegel, Koegel, Harrower, & Carter, 1999). Appropriate participation of parents in treatment leads to additional benefits that extend beyond the child and to the family, such as an increase in
the amount of positive affect a parent directs toward his or her child (Koegel, Bimbela, & Schreibman, 1996; Schreibman, Kaneko, & Koegel, 1991), an increase in parental confidence in handling the child’s problematic behaviors (Smith, Buch, & Gamby, 2000), and a reduction in parental stress (Smith et al., 2000; McConachie & Diggle, 2007). Still, there is a lack of research on the factors that affect the adherence of parents to treatment recommendations. It is crucial that when parents are involved in the delivery of treatment they adhere to prescribed recommendations to optimize treatment effectiveness for their children (Watson, Foster, & Friman, 2006). For that reason, it is imperative that research focuses on barriers to parental adherence to treatment recommendations.

In early characterizations of ASD, the prominent belief was that poor parenting caused the child’s disorder (Kanner, 1949; Bettelheim, 1967). During this period, mothers were thought to display a lack of appropriate affection toward their child (i.e., refrigerator mothers), and fathers were considered weak and absent from their child’s life (Kanner, 1949; Bettelheim, 1967). As a consequence, parents were intentionally excluded from participating in interventions. Starting with Bernard Rimland (1964), there was a movement toward a biological basis for ASD and away from psychogenic causes of the disorder. O. Ivar Lovaas (e.g., Lovaas et al., 1973) was one of the first researchers to acknowledge the positive influence of parental participation in behavioral treatments. In fact, he argued that parents were of particular importance to behavioral treatments because of their role in generalizing learned skills outside of the therapy session (Lovaas et al., 1973). Others also began to argue that treatment gains for children with ASD would not be possible without the involvement of parents (e.g., Schopler & Reichler, 1971; see Vismara & Rogers, 2010, for a review), and in some circumstances,
the acquired skills of parents may be more therapeutic for the child than the time they spent with a trained therapist (Schopler & Reichler, 1971).

Since this re-characterization of the role of parents in ASD treatment, research has further showed that parents are vital in the continuity, maintenance, generalization, and outcomes of treatment. In fact, many treatments for children with ASD are designed to include parents (in varying degrees) in the therapeutic process. For example, some of the more common and effective current approaches, including Pivotal Response Training, the Denver Model, or Early Start Denver Model, integrate teaching and learning of skills in daily home activities, such as playtime and chores (Dawson et al., 2010; Vismara & Rogers, 2010).

Despite all of the benefits of involving parents in the treatment process, and the advent of new therapeutic models that include parents in therapy, very little research has been conducted to examine factors that affect parent participation in interventions. Parents of children with ASD experience a wide range of difficulties, such as increased parental stress, greater financial strain, longer childcare demands, limited support, and disrupted social activities, all of which may influence their role in their child’s treatment (Koegel et al., 1999). Interventions should be designed to address these difficulties experienced by parents of individuals with ASD so as to ensure treatment recommendations be implemented and followed through accordingly.

One common way of examining parent participation is to evaluate their adherence to treatment recommendations. Adherence is commonly defined as the active and deliberate behavior of an individual to follow recommended procedures without oversight from the professional who made the recommendations. Treatment adherence is measured
and defined differently in child and adult therapy (Nock & Kazdin, 2005). In child therapy, the parent is equally, if not more responsible, for the adherence to treatment recommendations (Nock & Kazdin, 2005). In adult therapy, the individual receiving therapy is solely accountable for their compliance to treatment recommendations (Nock & Kazdin, 2005). In the medical literature, where treatment adherence is most commonly studied, children from clinical populations have significantly better outcomes when families had greater adherence to treatment recommendations (Patterson & Chamberlain, 1994; Springer & Reddy, 2010; Reardon, Cukrowicz, Reeves, & Joiner, 2002).

Generally speaking, adherence to treatment recommendations has not been thoroughly investigated in the ASD population, with minimal efforts placed to understand factors that influence parental adherence with this specific clinical population despite the well-documented and profound life stressors faced by families with individuals with ASD (Koegel et al., 1999).

Moore and Symons (2009) was the first to conduct an in-depth examination of the adherence of parents of children with ASD to both medical and behavioral treatment recommendations. Moore and Symons developed a novel survey to measure parental adherence. The survey was divided into four sections: (1) family characteristics, (2) child characteristics, (3) adherence to behavioral treatment recommendations, and (4) adherence to medical treatment recommendations. Items in the family and child characteristics sections were developed based on the authors’ clinical experience as well as from examples in the adherence literature in the medical and behavioral health fields. Study participants were parents of children with ASD who filled out and returned the questionnaire, which they received in the mail. Participants who completed the measure
were primary caregivers of a child with ASD living in the same household and currently receiving behavioral or medical treatment recommendations for the management of problem behavior of their child with ASD. A total of 220 completed surveys were included in the study’s analyses.

There were two main findings from the Moore and Symons (2009) study. First, parents reported significantly greater adherence to medical treatment recommendations than behavioral treatment recommendations, specifically reinforcement- and punishment-based recommendations. Second, two significant predictors of parental adherence to treatment recommendations were identified. The first predictor was diagnosis; specifically, the child’s diagnosis predicted parental adherence to behavioral treatment recommendations, with parents of children with a parent-reported diagnosis of Asperger syndrome reporting lower levels of adherence when compared to children with a parent-reported diagnosis of autism or ASD. The second predictor was the relationship between diagnosis and marital status; that is, the interaction between diagnosis and marital status predicted adherence to medical treatment recommendations. In particular, single parents of children with a diagnosis of PDD-NOS or autism reported higher levels of adherence to treatment recommendations, but single parents of children with a diagnosis of Asperger syndrome or high-functioning autism reported substantially lower levels of adherence to treatment recommendations.

These findings confirmed some expectations, but raised additional questions. The finding that parents were more likely to adhere to medical treatment recommendations than behavioral treatment recommendations is expected as medical treatment recommendations are, in general, easier to follow than behavioral treatment recommendations.
recommendations (Moore & Symons, 2009). Medical treatment recommendations are clearly defined and implemented less frequently throughout the day than behaviorally-based treatment recommendations (Moore & Symons, 2009). One finding the authors had not anticipated was parents of children with a diagnosis of Asperger syndrome or high-functioning autism were less likely to adhere to behavioral treatment recommendations (Moore & Symons, 2009). This difference in adherence suggests that parents of children with a diagnosis of Asperger syndrome or high-functioning autism may not see the necessity to engage in recommended treatments because of their child’s relatively appropriate level of language development and academic success.

The other surprising finding from this study was that single parents of children with a diagnosis of PDD-NOS or autism were more likely to adhere to medical treatment recommendations than married parents of children in the same diagnostic groups. However, single parents of children diagnosed with Asperger syndrome or high-functioning autism reported less adherence to medical treatment recommendations. This disparity might be understood by the earlier explanation that parents of children with higher abilities and less impairment in symptomatology, by definition of the disorder, do not believe their child needs as much additional support as children with lower social and academic abilities. Additionally, it may be that single parents of children with Asperger syndrome or high-functioning autism decide the financial needs of the family are more pressing than the time and expense involved in adhering to medical treatment recommendations. Thus, if the child of a single parent is functioning relatively well,

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1The term “high-functioning autism” was used in Moore and Symons’ study [19] despite this term is not an official diagnosis of the DSM-IV-TR or in the proposed DSM-5 (Diehl, Tang, & Thomas, in press). We used this term in our study to be consistent with the original study.
there may be less of a desire on the parent’s part to adhere to treatment recommendations compared to a child with more impaired skills.

Moore and Symons’ (2009) work represented an initial attempt to address the treatment adherence assessment issue in parents of children with ASD, but there are significant design flaws in the study’s measure that must be considered when interpreting the results. First, the diagnosis of the child was not validated with a well-established diagnostic tool. Granted, that gold-standard diagnostic techniques, such as the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000), are time consuming and difficult to apply to large-scale studies conducted online or via mail. However, screening measures exist, such as the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003), which allow for identification of behaviors associated with ASD during early childhood and within the past three months. Without scores from a standardized screening measure, it cannot be confirmed that the children of the respondents met criteria for a true diagnosis of ASD. Accurate diagnosis is essential because two of the main findings from the study involved child diagnosis in relation to parental adherence to treatment recommendations. Moreover, accurate diagnosis in the overall literature is absolutely necessary to ensure that findings have appropriate clinical utility.

Another potential issue in Moore and Symons’ (2009) study is the use of categorical diagnoses within the disorder. Research has shown that ASD diagnoses are not categorical in nature (Mayes, Calhoun, & Crites, 2011). As the definition of ASD transitions away from a categorical definition of multiple, distinct subgroups within the disorder and toward a fluid continuum of core symptoms defining a spectrum disorder (DSM-5; dsm5.org), identifying the relationship between parental adherence to treatment
recommendations and categorical diagnoses of ASD is no longer as relevant. Thus, a more appropriate evaluation of the relationship between parental adherence to treatment recommendations and ASD would be to examine symptoms (and severity of symptoms, in particular) that define the disorder, rather than categorical diagnoses. A refined assessment of ASD symptoms along a continuum would allow for a more fine-grained analysis of the possible relationship between symptoms associated with the disorder and parental adherence to treatment recommendations.

The child’s current level of adaptive behavior functioning might also affect parental adherence to treatment recommendations. Adaptive behaviors are described as the necessary skills required to function appropriately in daily life and to care for oneself. To date, there are no studies in the ASD literature that have examined the relationship between a child’s adaptive behavior functioning and parental adherence to treatment recommendations, even though other relationships with adaptive behaviors have been studied, such as parental treatment priorities (Pituch et al., 2011). In Pituch and colleagues’ (2011) study, parent treatment priorities tended to be related to the child’s deficits in adaptive behavior functioning; that is, parents of children with ASD were more likely to prioritize treatments designed to improve their child’s targeted behaviors. However, when evaluating deficits in communication and academics, parents prioritized treatments based on their child’s emerging skills.

A more recent study by Moore and Symons (2011) further examined parental adherence to treatment recommendations for individuals with ASD. In this study, parents of individuals with ASD were first trained to implement behavioral management skills based on the principles of ABA. Parents were then asked to rate their level of adherence
in implementing the behavioral management skills to their child in every day activities, level of support from family and friends, child characteristics, and parent characteristics. Parents in this study reported they were less likely to adhere to behavioral management skills in natural environments (that is, in the home). Additionally, the authors discovered that when parents agreed on when and how to implement the behavioral management skills in the home, they were more likely to adhere to the treatment. Lastly, and perhaps the most significant finding from the study, three predictors of parental adherence were identified. The predictors were self-perception of effectiveness to change their child’s behavior, confidence in the treatment to change their child’s behavior, and acceptance of the individual with ASD in the family and community. This study extends the limited knowledge of treatment adherence, but does not identify other factors that influence parental adherence to treatment recommendations.

A recent pilot study by Tang and colleagues (2012) aimed to replicate the findings from Moore and Symons (2009), in addition to exploring how individual differences in symptom severity and current adaptive functioning affect parental adherence to treatment recommendations. For this pilot study, primary caregivers of individuals with ASD completed four questionnaires online. Participants first completed the Parental Adherence Questionnaire, which was a modification of Moore and Symons’ (2009) questionnaire. Participants then completed both the “Lifetime” and “Current” versions of the SCQ as a way to measure ASD symptom severity across their child’s lifetime and within the past three months. Finally, participants completed the Adaptive Behavior Assessment System-Second Edition (ABAS-II; Harrison & Oakland, 2003) to measure their child’s current adaptive behavior functioning. When parent-reported diagnosis was
used, parental adherence was correlated with only behavioral treatment recommendations, a finding which was identical to Moore and Symons (2009). When controlling for parent-reported diagnosis of their child, the SCQ Current total summary score (that is, level of ASD symptoms observed in the past three months) accounted for a significant proportion of variance in parental adherence to both behavioral and medical treatment recommendations over and above the effects of diagnosis alone. Surprisingly, overall level of current adaptive behavior functioning was not correlated with parental adherence to either behavioral or medical treatment recommendations. This pilot study suggested ASD symptom severity is predictive of parental adherence to treatment recommendations over and above diagnosis alone, but current adaptive behavior functioning of the child does not influence parental adherence to treatment recommendations.

A number of questions were not addressed in this pilot study. The study only examined the total scores of the SCQ Current and ABAS-II rather than individual items or domain scores. This limitation is especially crucial given that the child’s current adaptive behavior functioning was not correlated with parental adherence to behavioral or medical treatment recommendations. It is possible that domain scores on the ABAS-II are more likely to predict parental adherence to treatment recommendations than the overall summary score. Additionally, information from the SCQ Lifetime was not analyzed, thus ignoring potentially useful information about if and how changes in symptom severity over the course of the child’s life play a role in parental adherence to treatment recommendations. Furthermore, the findings from the pilot study were based
on a small sample size \((n = 95)\). A larger sample size is needed to determine if findings may be applied to the larger ASD population.

   Additionally, individual factors, such as the development of the child, could influence how much a parent is willing to invest personal involvement in the intervention. We believe parents are more willing to be involved in interventions when their child is younger as the introduction of interventions at an earlier age is associated with greater developmental improvement. Parents may be less likely to adhere to treatment recommendations when their child is older because of the perception that the older child will not experience developmental gains seen in younger children, the child is in school for the majority of the day with less time for afterschool therapies, and parents have learned to cope with the child’s deficits and may feel additional interventions are not needed. Although Moore and Symons (2009) did not find a relationship between current age of the child and parental adherence, we examined this relationship in our study because it was unclear in the earlier study the precise age range of the children with ASD. Therefore, it may be that the nonsignificant finding surrounding age of the child with ASD in Moore and Symons’ study is not applicable to our study.

   Another individual factor to examine is the “improvement” in symptom severity. This was measured in our present study as the difference in the total scores of the SCQ Current and SCQ Lifetime, with a positive difference suggesting improvement in ASD symptoms, a negative difference suggesting symptoms have worsened, and no difference implying symptoms have remained constant. It is possible as a child exhibits milder symptoms characteristic of the disorder, parents will be less likely to adhere to treatment recommendations due their child’s improvement. Research has shown that individuals
with “higher functioning” autism display larger discrepancies between IQ and adaptive behavior functioning as they mature in chronological age; that is, the discrepancy between IQ and adaptive behavior functioning widens as individuals with “higher functioning” autism age, thus re-emphasizing the importance for parents to adhere to treatment recommendations as their child ages and “improves” (Kanne et al., 2011).

There are also a number of additional family contextual factors that have been shown in the medical literature to influence treatment adherence in other clinical populations (e.g., Fielding & Duff, 1999) that have yet to be examined in families with individuals with ASD. It has been suggested that poor family support is associated with low treatment adherence. Support is needed for parents to cope with the rigors and demands of treatment recommendations (Fielding & Duff, 1999). Perhaps an extension of this previous finding will be to examine the living environment of parents; that is, families whose parents both live in the same household (a clear example of constant family support in the home) will exhibit higher rates of adherence to treatment recommendations than parents living apart. It has also been shown that families with more financial strain (that is, families in the low socioeconomic group) experience greater difficulties adhering to treatment recommendations, keeping appointments, and accurately reporting child’s behavior to treatment (Fielding & Duff, 1999). It is believed that financial strain is considered a treatment barrier and indirectly influences adherence to treatment recommendations (Fielding & Duff, 1999). Lastly, the number of individuals with a disability living in the household may also impact parental adherence to treatment recommendations. More individuals in the same household with a disability will lead to lower parental adherence to treatment recommendations as the demands of
tending to more than one individual with a disability will increase and focus of treatment will be shared amongst all individuals with a disability, rather than just the individual with ASD.

In sum, research on parental adherence to treatment recommendations for individuals with ASD is greatly underrepresented in the field. Thus far, only two published studies (Moore & Symons 2009; 2011) have examined the factors influencing parental adherence to treatment recommendations. One of these studies concluded that medical treatment recommendations were more likely to be adhered to than behavioral treatment recommendations, parents of individuals reported to be diagnosed with Asperger syndrome were less likely to adhere to behavioral treatment recommendations than medically-based treatment recommendations, and the relationship between a child’s diagnosis and parental marital status influenced parental adherence to treatment recommendations (Moore & Symons, 2009). A pilot study (Tang et al., 2012) demonstrated that symptom severity was more informative in predicting parental adherence to treatment recommendations than parent-reported diagnosis. However, results from the pilot study stemmed from a small sample and symptom severity was defined within the parameters of the preliminary analyses as the total score on the SCQ Current. Moreover, there was no evidence of an association between current adaptive behavior functioning of the individual with ASD and parental adherence, but again, analyses were conducted on a small sample and incorporated only the overall summary score on the ABAS-II. Furthermore, analysis of the data did not evaluate if and how individual or family contextual variables, such as change in ASD symptom severity over
the course of the child’s life, annual family income, parental cohabitation, and number of individuals with a disability living in the household, influence parental adherence to treatment recommendations.

II. Purpose of Study

The purpose of our study is fourfold: (1) to replicate findings from Moore and Symons’ study (2009); specifically the relationships among child diagnosis, parental marital status, and parental adherence to treatment recommendations, (2) to evaluate if ASD symptomatology is a better predictor of parental adherence to treatment recommendations than diagnosis, (3) to examine if specific areas of current adaptive behavior functioning influences parental adherence to treatment recommendations; particularly Conceptual and Practical domains, and (4) to determine if additional individual and family contextual factors beyond parental marital status, play a role in parental adherence to treatment recommendations.

III. Hypotheses

First, we hypothesize that the results from our study will parallel findings from Moore and Symons (2009). We believe that parents of individuals with ASD will be more likely to adhere to medically-based treatment recommendations than behaviorally-based treatment recommendations. Additionally, the presence of an Asperger syndrome diagnosis will be related to lower levels of parental adherence to behavioral treatment recommendations when compared to a more serious diagnosis of autism or ASD. Furthermore, unmarried parents of individuals with a diagnosis of Asperger syndrome or
high-functioning autism will be less likely to adhere to medical treatments than married parents.

Second, we hypothesize that ASD symptomatology will be more predictive of parental adherence to treatment recommendations above and beyond ASD diagnosis, similar to the findings by Tang and colleagues (2012). We also predict greater presentation of self-injurious behavior in individuals with ASD will be associated with higher levels of parental adherence to behavioral and medical treatment recommendations, as these behaviors may put the child and others (e.g., siblings, classmates) in danger of physical harm and greater efforts will be placed to minimize these behaviors. Additionally, parents of individuals presenting with greater repetitive body movements (e.g., handflapping) will be more apt to adhere to behavioral treatment recommendations because these behaviors tend to be more distracting to the self and others, and may impede on learning.

Third, we hypothesize that specific areas of current adaptive behavior functioning will influence parental adherence to treatment recommendations. Although the pilot study conducted by Tang and colleagues (2012) demonstrated that the child’s current adaptive behavior functioning did not affect parental adherence to treatment recommendations, the Conceptual and Practical domains of the ABAS-II may be more informative of parent behavior as these areas of daily functioning reflect the child’s learning (both self-care and academic) in the home and school.

Lastly, we predict that certain individual and family contextual factors will have an impact on parental adherence to treatment recommendations. In terms of individual factors, the current age and change in ASD symptom severity of the individual with ASD
(as measured by the difference in total scores of the SCQ Lifetime and SCQ Current) will influence parental adherence to treatment recommendations. Specifically, we expect that an “improvement” in ASD symptoms will be associated with lower levels of parental adherence. We believe that as a child’s ASD symptoms improve, parents will be more likely to relax on properly following with treatment recommendations.

In terms of family contextual factors, three key factors will be explored as predictors of parental adherence to treatment recommendations: (1) annual family income, (2) parental cohabitation, and (3) number of individuals in the household with a disability. We believe families with lower annual family income will be less likely to adhere to treatment recommendations as treatment services may be taxing on the family’s financial resources. We also believe that parents residing in separate households, regardless of marital status, will be less likely to adhere to treatment recommendations as two-parent systems have more benefits (e.g. family support) that may lead to greater parental adherence to treatment recommendations than single-parent systems (Weinraub & Wolf, 1983). Lastly, the more individuals with a disability in the household will be more challenging for parents to direct all attention and efforts on only the individual with ASD.
METHOD

I. Participants

Participants were 202 parents of individuals diagnosed with an ASD. Participants were recruited through several venues including, but not limited to: (1) the Laboratory For Understanding Neurodevelopment (F.U.N. Lab) participant database, (2) the F.U.N. Lab listserv, (3) the Sonya Ansari Center for Autism listserv, (4) ASD information websites (e.g., Autism Speaks), and (5) local and national parent organizations. Inclusion criteria for participants were: (1) the respondent was a primary caregiver of an individual with ASD residing in the same household, (2) the respondent was 18 years or older, (3) the individual diagnosed with ASD was 21 years or younger, and (4) the individual with ASD had a SCQ Lifetime total score of 15 or greater. We used the cutoff of 15 on the SCQ Lifetime as this is the total score that has been shown to differentiate individuals on the spectrum from those who do not meet diagnostic criteria for the spectrum (Berument, Rutter, Lord, Pickles, & Bailey, 1999). Families with multiple children diagnosed with ASD were able to participate in the study as many times as there were number of individuals with an ASD diagnosis in the household. Participants voluntarily entered into a drawing for four $20 gift certificates upon completion of the study. This study received approval from the University of Notre Dame Human Subjects Institutional Review Board.

A total of 335 individuals started the consenting process. Eighteen individuals (5.4%) did not consent to participate in the study. Of the 317 consented respondents, 133
participants (42.0%) met all criteria established for this study: (a) completed the Parental Adherence Questionnaire (PAQ), SCQ Lifetime, SCQ Current, and ABAS-II, (b) SCQ Lifetime total score was greater than or equal to 15, and (c) correctly answered four or five of the five special items to detect careless responses in the SCQ Lifetime, SCQ Current, and ABAS-II. An additional 69 participants were included in the final sample who met the above criteria but did not complete the ABAS-II. These participants were included in all analyses not involving the ABAS-II.

II. Materials and Procedure

Participants completed the study from their personal computers. All data was collected online via Qualtrics, a secure online website. The four questionnaires that comprise the study took approximately 45 minutes to one hour for participants to complete. A direct link on the F.U.N. Lab website, in emails, or on community websites redirected participants to the online study, who were provided with a one-time use password. Participants were then presented with an online consent form, in which they consented to participate before being presented with the first questionnaire. Upon completion of the last questionnaire, participants were asked to voluntarily provide their email addresses if they wanted to be entered in a raffle for a monetary prize of $20.

i. Parental Adherence Questionnaire

The Parental Adherence Questionnaire was modified from a questionnaire developed by Moore and Symons (2009; see Appendix A). The original questionnaire asked questions about family and child characteristics, and parental adherence to
behavioral and medical treatment recommendations. A number of additions and deletions of items from the original questionnaire were made in order to answer our research questions (see Appendix B). For example, additional items were added addressing the relationship of person completing the questionnaires (mother, father, or other primary caregiver of the individual with ASD), parental cohabitation, and employment information of both parents.

ii. Social Communication Questionnaire

The Social Communication Questionnaire (SCQ; Rutter et al., 2003) is a brief parent-report questionnaire used to verify the child’s diagnosis and to measure the child’s current level of ASD symptomatology. The SCQ is a brief parent-report questionnaire. It is commonly used in research and clinical settings as a screening tool to evaluate ASD symptoms in individuals who have or have not yet been diagnosed with ASD. There are two versions of the questionnaire, Lifetime and Current. The Lifetime version looks at an individual’s entire developmental history and is useful for confirming an individual’s diagnosis. The Current version looks at the individual’s level of symptomatology within the last three months. Respondents answer 40 questions with either a yes or a no, with the total score of 15 or greater on the Lifetime version used as a cutoff for meeting criteria of a diagnosis of ASD. Each version of the SCQ provides a total score; currently, there are no subscales on the SCQ. Instead, we used specific items in the measure to examine which symptoms of the disorder best predicted parental adherence to treatment recommendations.
The Adaptive Behavior Assessment System-Second Edition (ABAS-II; Harrison & Oakland, 2003) is a brief parent-report questionnaire used to measure current adaptive behavior functioning of the children of the study participants. The questionnaire assesses the daily living skills of individuals with an intellectual and/or developmental disability. The ABAS-II is divided into specific age ranges, starting at 0 years and up to 89 years; however, this study only utilized the ABAS-II Parent/Primary Caregiver Form (Ages 0-5) and the ABAS-II Parent Form (Ages 5-21). The ABAS-II generates a total score (General Adaptive Composite or GAC), three domains and ten adaptive skill areas. The Conceptual domain is composed of communication skills, functional academics, and self-direction. The Social domain consists of social and leisure skills. The Practical domain addresses self-care, home or school living, community use, work (for working-age individuals), and health and safety. These three domains and ten adaptive skill areas cover practical, every day skills that individuals need to function independently.

Respondents answer questions based on a 4-point Likert-type scale. Answer choices are: (1) Is not able to, (2) Never or almost never when needed, (3) Sometimes when needed, and (4) Always or almost always when needed. All scores provided are based on age-related norms. A measure of the child’s current adaptive behavior functioning was collected rather than learning (IQ) level as interventions work on improving adaptive behavior skills and not necessarily on increasing IQ level.
RESULTS

A comparison of the reported family characteristics from our sample and the sample from Moore and Symons (2009) is presented in Table 1. In both samples, the majority of the families lived in suburban areas, reported to be part of the middle class (with slightly more families in our sample reporting to be part of the lower class), and majority of parents were married. Additionally, families in both studies reported moderate to high level of father involvement with the individual with ASD. However, families in our sample had more children living at home than the families in Moore and Symons’ study.

Additional family information was collected in our study that was not originally collected by Moore and Symons (2009) and is presented in Table 1. Data was collected about which caregiver completed the online survey as there may be possible differences in adherence to treatment recommendations between mothers, fathers, and other caregivers. Mothers were 17 times more likely to participate in our study than fathers. Other factors, such as parental cohabitation and employment, could also affect treatment adherence. Parents in our sample were more likely to live in the same household. Roughly half of the mothers were employed and of those mothers, more than half were employed full-time, working about 42 hours per week. The majority of fathers were employed full-time, working on average 44 hours per week. Information was also collected about the number of individuals with ASD and the number of individuals diagnosed with a non-ASD disability or disorder living in the same household. Majority
of respondents reported only one individual with ASD living in the same home and did not have another individual with a developmental disability (not ASD) living in the household. There were, on average, two legal dependents in the household.

TABLE 1
DEMOGRAPHIC AND FAMILY INFORMATION

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<tr>
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<th>Tang &amp; Diehl&lt;sup&gt;a&lt;/sup&gt;</th>
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<td>Three</td>
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<td>Four or more</td>
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<td>91</td>
<td>45.0</td>
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<tr>
<td></td>
<td><strong>Tang &amp; Diehl</strong>$^a$</td>
<td></td>
<td><strong>Moore &amp; Symons</strong>$^b$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
<td>Percent</td>
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<tr>
<td><strong>Mother’s Employment Status</strong></td>
<td><strong>Father’s Working Status</strong></td>
<td><strong>Mother’s Employment Status</strong></td>
<td><strong>Father’s Employment Status</strong></td>
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<td>Full-time</td>
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<td>13.9</td>
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<td><strong>Individuals with ASD living at home</strong></td>
<td><strong>Individuals with DD living at home</strong></td>
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<td>10</td>
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<td><strong>Mean</strong></td>
<td><strong>Min, Max</strong></td>
<td><strong>Min, Max</strong></td>
<td><strong>Min, Max</strong></td>
<td><strong>Min, Max</strong></td>
</tr>
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<td>NC</td>
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<td>Hours per week father employed</td>
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<td>1, 11</td>
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*Note.* NC = not collected.

*Note.* DD = developmental disability.

$^a$n = 218.

$^b$n = 220.
A comparison of the reported child characteristics of this study sample and Moore and Symons’ (2009) sample is presented in Table 2. In both samples, autism and Asperger syndrome accounted for most of the diagnoses; however, autism accounted for 40% of the diagnoses in Moore and Symons’ sample compared to only 29% in our sample. Additionally, a diagnosis of ASD was almost three times more common in our sample. This difference in the reported number of ASD cases in the two studies is most likely attributed to the proposed changes to DSM-5 where diagnoses will be subsumed under autism spectrum disorder.

A number of child characteristics were collected in our study that were not originally reported in Moore and Symons’ (2009) study, or were edited to provide more detailed information about our sample (see Table 2). The current age of the individual with ASD and the age in which they received their first diagnosis were collected by Moore and Symons, but those numbers were not reported and we cannot make any comparisons between the samples. About 70% of the individuals with ASD in our sample had average or above average IQ. In the original study, Moore and Symons asked respondents to identify their child’s learning challenges as none, mild (IQ 55-70), moderate (IQ 40-55), or severe/profound (IQ 20-40). In their sample, individuals with ASD had either no or mild learning challenges. Although the items and the response options are not identical, the individuals with ASD in both samples appear to have minimal cognitive challenges.
<table>
<thead>
<tr>
<th></th>
<th>Tang &amp; Diehl&lt;sup&gt;a&lt;/sup&gt;</th>
<th></th>
<th>Moore &amp; Symons&lt;sup&gt;b&lt;/sup&gt;</th>
<th></th>
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<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
<td>Frequency</td>
<td>Percent</td>
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<td>19.3%</td>
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<tr>
<td>Asperger syndrome</td>
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<td>24.8%</td>
<td>69</td>
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<td>HFA</td>
<td>9</td>
<td>4.5%</td>
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<td>Autism</td>
<td>59</td>
<td>29.2%</td>
<td>88</td>
<td>40.0%</td>
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<td>ASD</td>
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<tr>
<td>Female</td>
<td>37</td>
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<td><strong>IQ</strong></td>
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<td>Below average</td>
<td>60</td>
<td>29.7%</td>
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<tr>
<td>Average</td>
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<td>41.1%</td>
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<td>59</td>
<td>29.2%</td>
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<td>NC</td>
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<td><strong>Cognitive Challenge</strong></td>
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<td>NC</td>
<td>92</td>
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<td>NC</td>
<td>11</td>
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<td>NR</td>
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<td><strong>Age at first diagnosis</strong></td>
<td>4.1</td>
<td>1, 16</td>
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</table>

<sup>Note.</sup> NC = not collected.
<sup>Note.</sup> NR = not recorded.
<sup>Note.</sup> PDD-NOS = Pervasive Developmental Disorder – Not Otherwise Specified; HFA = high-functioning autism; ASD = autism spectrum disorder.
<sup>a</sup>n = 218.
<sup>b</sup>n = 220.
I. Reporting Consistency

To confirm respondents were consistently reporting their adherent behavior to treatment recommendations, correlations were calculated for parent-reported modifications to treatment recommendations without consultation from their professional care provider and adherence to treatment recommendations as a continuous variable and as a dichotomous variable. The value for parental adherence to treatment recommendations ranged from 0 to 1, where a value of 0 represented no parental adherence to treatment recommendations and a value of 1 represented perfect adherence to treatment recommendations, as used in Moore and Symons’ analyses (2009). If a respondent reported 100% adherence to treatment recommendations, he/she should have also reported not making any changes to treatment recommendations without consultation from their professional care provider. Participants who did not report at least one treatment recommendation were not included in analyses pertaining to measurement of adherence to treatment recommendations, as there were no opportunities for the respondent to follow or not follow recommended treatments. Therefore, a total of 171 participants were included in analyses on behavioral treatment recommendations, and a total of 129 participants were included in analyses on medical treatment recommendations.

A point biserial correlation was conducted to examine the relationship between parent-reported modifications to treatment recommendations and parental adherence to behavioral treatment recommendations. The correlation was positive for behavioral treatment recommendations ($r_{pb} = .35, p < .001$) and medical treatment recommendations
(r_{pb} = .32, p < .001), suggesting that when parents reported 100% adherence to treatment recommendations, they also reported they did not make any changes to treatment recommendations.

II. Analyses

We first hypothesized that parents are more likely to adhere to medical treatment recommendations than behavioral treatment recommendations. A paired samples t-test was conducted to compare parental adherence to medical treatment recommendations to adherence to behavioral treatment recommendations. For these analyses, 116 participants were included in these analyses because they reported at least one behavioral treatment recommendation and at least one medical treatment recommendation. Similar to Moore and Symons (2009), parents are more likely to adhere to medical treatment recommendations than behavioral treatment recommendations, t(115) = 4.33, p < .001, d = .50.

Additionally, we predicted parents of individuals with a diagnosis of Asperger syndrome would report lower levels of adherence to behavioral treatment recommendations compared to parents of individuals with a diagnosis of autism or ASD. Because we were only interested in examining parents of individuals with a diagnosis of Asperger syndrome, autism or ASD, and endorsed at least one behavioral treatment recommendation, a total of 131 participants were included in these analyses. We first conducted a one-way between subject analysis of variance (ANOVA) to examine the effect of the child’s diagnosis on parental adherence to behavioral treatment recommendations. The results of the one-way between subject ANOVA showed a significant effect of the child’s diagnosis (Autism, ASD, or Asperger syndrome) on
parental adherence to behavioral treatment recommendations \[F(2, 128) = 5.02, p < .01, \eta^2_{\text{partial}} = .13]\.

We then conducted a Tukey HSD post-hoc test to determine which of the three groups (Autism, ASD, or Asperger syndrome) differed from each other; specifically, if there was a difference between parents of individuals with a diagnosis of Asperger syndrome and parents of individuals with a diagnosis of autism or ASD. The results from the Tukey post-hoc test indicated that the mean adherence score of parents of individuals with a diagnosis of Asperger syndrome \((M = .63, SD = .37)\) was significantly lower from parents of individuals with a diagnosis of autism \((M = .84, SD = .24)\), with a mean difference of -.21 \((p < .01, 95\% \text{ CI } [-.37, -.05])\). However, the mean adherence score of parents of individuals with a diagnosis of Asperger syndrome did not significantly differ from the mean adherence score of parents of individuals with a diagnosis of ASD \((M = .74, SD = .36)\), with a mean difference of -.10 \((p = .32, 95\% \text{ CI } [-.27, .07])\). Additionally, the mean adherence score of parents of individuals with a diagnosis of ASD did not significantly differ from the mean adherence score of parents of individuals with a diagnosis of autism, with a mean difference of -.11 \((p = .27, 95\% \text{ CI } [-.27, .06])\). These results suggest that parents of individuals with a diagnosis of Asperger syndrome reported lower adherence to behavioral treatment recommendations than parents of individuals with a diagnosis of autism. There was not a difference in parental adherence to behavioral treatment recommendations between parents of individuals with a diagnosis of Asperger syndrome and parents of individuals with a diagnosis of ASD.

For our last prediction of our first hypothesis, we predicted unmarried parents of individuals with a diagnosis of Asperger syndrome or high-functioning autism would be
less likely to adhere to medical treatment recommendations than parents who are married. For these analyses, we initially examined a total of 44 participants as we were only interested in parents of individuals with a diagnosis of Asperger syndrome or high-functioning autism who had reported at least one medical treatment recommendation. A point biserial correlation showed no relationship between marital status of parents of individuals with a diagnosis of Asperger syndrome or high-functioning and parental adherence to medical treatment recommendations ($r_{pb} = .01, p = .96$). These findings indicate that unmarried and married parents of individuals with Asperger syndrome or high-functioning autism do not differ in adherence to medical treatment recommendations.

We further examined this relationship between marital status and parental adherence to medical treatment recommendations for all participants who reported at least one medical treatment recommendation. Therefore, a total of 129 participants were included in these analyses. A point biserial correlation did not show a relationship between marital status and parental adherence to medical treatment recommendations ($r_{pb} = .13, p = .15$). Taken both results together, marital status does not influence parental adherence to medical treatment recommendations.

For our second hypothesis, we first predicted current ASD symptomatology would be more predictive of parental adherence to treatment recommendations than diagnosis. The SCQ Current total score was used to measure current ASD symptomatology, where a higher total score on this measure identified a greater presentation of ASD symptoms. A Pearson’s $r$ correlation showed no relationship between current ASD symptomatology and parental adherence to behavioral treatment
recommendations ($r = .06, p = .43$). We then conducted a hierarchical linear regression with parental adherence to behavioral treatment recommendations as the dependent variable and current ASD symptomatology and child’s diagnosis as the independent variables. In the first step of the model we entered child’s diagnosis and in the second step of the model we entered current ASD symptomatology as measured by the SCQ Current total score. When controlling for child’s diagnosis, current ASD symptomatology did not account for a significant proportion of variance in parental adherence to behavioral treatment recommendations over and above the effects of the child’s diagnosis alone [$R^2 = .07, F(1, 165) = .07, p = .79$].

We then examined the relationship between current ASD symptomatology and parental adherence to medical treatment recommendations. We first conducted a Pearson’s $r$ correlation between current ASD symptomatology (as measured by the SCQ Current total score) and parental adherence to medical treatment recommendations. Results from this analysis showed no statistically significant relationship ($r = .07, p = .46$). We then conducted a hierarchical linear regression, with parental adherence to medical treatment recommendations as the dependent variable, and child’s diagnosis and current ASD symptomatology as the independent variables. At the first step of the model we entered diagnosis and at the second step of the model we entered SCQ Current total score. When controlling for child’s diagnosis, current ASD symptomatology did not account for a significant proportion of variance in parental adherence to medical treatment recommendations over and above the effects of diagnosis alone [$R^2 = .10, F(1, 123) = .78, p = .38$].
For the second part of our second hypothesis, we predicted that greater presentation of self-injurious behavior would be related with higher parental adherence to treatment recommendations. Current self-injurious behavior was measured by question 17 on the SCQ Current as a dichotomous variable; that is, participants were identified as either endorsing or not endorsing this item on the SCQ Current. The results from a point biserial correlation did not show a significant relationship between presentation of self-injurious behavior and parental adherence to behavioral treatment recommendations ($r_{pb} = -.02, p = .78$). These results suggest that parental adherence to behavioral treatment recommendations is not influenced by a child’s engagement in deliberate, self-injurious behavior within the past three months.

We then examined the relationship between current self-injurious behavior and parental adherence to medical treatment recommendations. We conducted a point biserial correlation and results showed there was not a significant relationship between self-injurious behavior and parental adherence to medical treatment recommendations ($r_{pb} = -.02, p = .86$). These results showed that current self-injurious behavior did not influence parental adherence to medical treatment recommendations.

For our last prediction of our second hypothesis, we hypothesized parents who reported current presentation of repetitive body movement, such as handflapping, would be more likely to adhere to behavioral treatment recommendations. Current presentation of repetitive body movements was measured by questions 15 and 16 on the SCQ Current. We conducted a Pearson’s $r$ correlation between current repetitive behaviors and parental adherence to behavioral treatment recommendations and found a nonsignificant relationship ($r = .02, p = .78$). Contrary to what we hypothesized, parental adherence to
behavioral treatment recommendations is not influenced by a presentation of repetitive body movements in their child.

For the first part of our third hypothesis, we predicted that a child with greater current adaptive behavior functioning, as measured by the General Adaptive Behavior Composite (GAC) on the ABAS-II, would be related to lower parental adherence to treatment recommendations. We first examined the relationship between current adaptive behavior functioning and parental adherence to behavioral treatment recommendations. A Pearson’s r correlation was conducted between GAC and parental adherence to behavioral treatment recommendations. Results from this correlation were not statistically significant \((r = -.08, p = .30)\), suggesting that overall current adaptive behavior functioning of an individual with ASD does not influence parental adherence to behavioral treatment recommendations.

To assess parental adherence to medical treatment recommendations, we conducted a Pearson’s r correlation between current adaptive behavior functioning, as measured by the GAC on the ABAS-II, and parental adherence to medical treatment recommendations. Results showed a negative correlation between a current adaptive behavior functioning and parental adherence to medical treatment recommendations \((r =-.18, p < .05)\). To further examine this relationship, we conducted a hierarchical linear regression between child diagnosis and current adaptive behavior functioning. When controlling for diagnosis, overall adaptive behavior functioning accounted for a significant proportion of variance in parental adherence to medical treatment recommendations over and above the effects of diagnosis alone \([R^2 = .10, F(1, 121) = 4.31, p < .05]\). That is, current adaptive behavior functioning of the child better predicted
parental adherence to medical treatment recommendations than the child’s diagnosis alone.

For the second part of our third hypothesis, we hypothesized the Conceptual domain on the ABAS-II would be more predictive of parental adherence to treatment recommendations than diagnosis. To test the relationship between the Conceptual domain and parental adherence to behavioral treatment recommendations, we conducted a Pearson’s r correlation and found the Conceptual domain was not significantly correlated with parental adherence to behavioral treatment recommendations \( (r = -.09, p = .27) \).

We further examined this relationship and conducted a hierarchical linear regression with child diagnosis and the score on the Conceptual domain. In the first step of the model we entered diagnosis, and in the second step of the model we entered the Conceptual domain score. When controlling for diagnosis, the Conceptual domain did not account for a significant proportion of variance in parental adherence to medical treatment recommendations over and above the effects of diagnosis alone \( \left[R^2 = .08, F(1, 155) = .03, p = .86\right] \). Based on these results, we conclude that the skills captured in the Conceptual domain on the ABAS-II do not influence nor predict parental adherence to behavioral treatment recommendations.

We then examined the relationship between the Conceptual domain and parental adherence to medical treatment recommendations. A Pearson’s r correlation showed a trend toward a relationship between Conceptual domain and parental adherence to medical treatment recommendations \( (r = -.16, p = .07) \). We then conducted a hierarchical linear regression to see if the Conceptual domain better predicted parental adherence to
medical treatment recommendations than diagnosis alone. Parental adherence to medical treatment recommendations was the dependent variable, and diagnosis and Conceptual domain were the independent variables. When controlling for the child’s diagnosis, we found a trend for the Conceptual domain to account for a proportion of variance in parental adherence to medical treatment recommendations over and above the effects of diagnosis alone \([R^2 = .09, F(1, 122) = 2.71, p = .10]\). That is, there was a trend for scores on the Conceptual domain to better predict parental adherence to medical treatment recommendations than diagnosis alone.

For the last part of our third hypothesis, we hypothesized that the score on the Practical domain on the ABAS-II would be predictive of parental adherence to treatment recommendations. We first conducted a Pearson’s \(r\) correlation to test the relationship between the Practical domain composite score and parental adherence to behavioral treatment recommendations, and did not find a significant relationship \((r = -.06, p = .44)\). We then conducted a hierarchical linear regression between child diagnosis and the composite score on the Practical domain. In the first step of the model we entered diagnosis, and in the second step of the model we entered the Practical domain score. When controlling for diagnosis, the Practical domain did not account for a significant proportion of variance in parental adherence to behavioral treatment recommendations over and above the effects of diagnosis alone \([R^2 = .08, F(1, 155) = .37, p = .54]\). We therefore conclude the skills captured in the Practical domain do not influence nor predict parental adherence to behavioral treatment recommendations.

To test the relationship between Practical domain and parental adherence to medical treatment recommendations, we first conducted a Pearson’s \(r\) correlation.
Results from this analysis showed a negative correlation between the Practical domain and parental adherence to medical treatment recommendations ($r = -.19, p < .05$). To further examine this relationship, we then conducted a hierarchical linear regression with parental adherence to medical treatment recommendations as the dependent variable, and diagnosis and the Practical domain as the independent variables. When controlling for child’s diagnosis, the Practical domain accounted for a significant proportion of variance in parental adherence to medical treatment recommendations over and above the effects of diagnosis alone [$R^2 = .10, F(1, 122) = 4.28, p < .05$]. Therefore, scores on the Practical domain better predicted parental adherence to medical treatment recommendations than the child’s diagnosis. Based on these results, skills captured on the Practical domain on the ABAS-II both influence parental adherence to medical treatment recommendations; that is, when a parent reports greater skills in this domain, they are less likely to adhere to medical treatment recommendations. Moreover, the score on the Practical domain better predicts adherence to medical treatment recommendations than the child’s diagnosis alone.

For our fourth hypothesis, we initially proposed five individual and familial factors believed to contribute to parental adherence. The five factors we identified were: (a) change in ASD symptoms (as measured by the difference between SCQ Lifetime and SCQ Current total scores), (b) current age of the child, (c) annual family income, (d) parental cohabitation, and (e) number of additional individuals with an ASD diagnosis or developmental disability living in the household. For each factor of the risk factor index, we identified a participant’s response as No Risk, Moderate Risk, or High Risk by the factor’s standard deviation. Responses were considered No Risk or High Risk if it was
one standard deviation or greater below or above the mean (depending on the content of
the question). Annual family income and parental cohabitation had three levels in their
responses that easily translated to the three group assignments.

A total risk ranged from 0 through 10, with a total score of 0-3 was considered No
Risk, 4-6 as Moderate Risk, and 7-10 as High Risk for low parental adherence to
treatment recommendations. Using this risk factor index, 2.9% of our sample was
considered at high risk for poor parental adherence to behavioral treatment
recommendations, and 0.0% of our sample was considered at high risk for poor parental
adherence to medical treatment recommendations. Families categorized as high risk for
poor parental adherence to behavioral treatment recommendations reported their child’s
ASD symptoms either remained constant or improved (as measured by the difference in
SCQ Lifetime and SCQ Current total scores). Also, the age of the child with ASD was
between 10 to 16 years. These families all reported being in the middle class, no
significant differences in parental cohabitation, and had additional individuals in the
household diagnosed with an ASD or developmental disability (range from one through
five individuals).

Unfortunately, most of our proposed risk factors were individually not correlated
with parental adherence to either behavioral or medical treatment recommendations, and
predictably, the overall risk factor index was not significantly correlated with behavioral
($r = -.05, p = .49$), or medical ($r = .04, p = .67$) treatment adherence.
DISCUSSION

This study was designed to examine factors affecting parental adherence to treatment recommendations for children diagnosed with an ASD. Although a previous study (Moore & Symons, 2009) found that categorical diagnosis was a significant predictor of parental adherence, we predicted that variables such as ASD symptomatology or adaptive behavior functioning would be better predictors of parental adherence to treatment recommendations. Moreover, we sought to identify individual and familial contextual factors that may influence parental adherence. Overall, we found that adaptive behavior functioning (both the overall score and two domains) was predictive of parent adherence over and above what was accounted for by parent-reported diagnoses, although this pattern only held for parental adherence to medical treatment recommendations. Contrary to our predictions, we did not find a relationship between ASD symptom severity or our predicted familial and contextual factors and parental adherence. In this discussion, we will consider our sample and results in the context of the original Moore and Symons study, and examine the different patterns found for behavioral and medical treatment adherence.

I. Individual Factors

Because our study used a modified version of the original Moore and Symons (2009) questionnaire, it allowed for some direct comparisons between our two studies. Similar to the findings in Moore and Symons’ study, parents in our sample were more likely to adhere to medical treatment recommendations than behavioral treatment.
recommendations. Medical treatments are often simpler to follow (e.g., taking a medication at certain time periods), whereas behavioral treatment recommendations are often much more difficult to implement. Additionally, we found that parents of individuals diagnosed with Asperger syndrome were more likely to adhere to treatment recommendations (both behavioral and medical) than parents of individuals diagnosed with autism. This difference in reported parental adherence did not exist between parents of individuals diagnosed with Asperger syndrome and parents of individuals diagnosed with ASD. It is striking that our findings on these questions so closely mimicked the original Moore and Symons study, and it reinforces the finding that an individual’s diagnosis, or factors involved with that particular diagnosis, seem to have a relationship to parental adherence.

Contrary to what we predicted, a child’s current presentation of ASD symptoms (as measured by the SCQ Current total score) did not influence parental adherence to behavioral or medical treatment recommendations. This finding was surprising given that there is a movement away from the categorical diagnoses used in DSM-IV-TR and toward a spectrum diagnosis with levels of severity. We also did not find relationships between specific items (repetitive behaviors, self-injurious behavior) and parental adherence. The nonsignificant findings, however, may have been affected by our inclusion criteria established at the beginning of the study. We only included participants who reported a total score of 15 or greater on the SCQ Lifetime as this was a way to identify individuals who would most likely meet an ASD diagnosis. Therefore, by removing a portion of potential responses, this may have inadvertently affected our analyses involving the SCQ Current and SCQ Lifetime measures. Still, we believe that
this level of diagnostic confirmation is crucial for this study (and all ASD studies), because there is considerable variability in community diagnoses (both state-to-state and between countries), and it facilitates more valid comparisons between studies. Future studies might consider using an additional measure of symptomatology that was not used for diagnostic confirmation as the measure used in the analyses.

When we evaluated the relationship between a child’s current adaptive behavior functioning and parental adherence to treatment recommendations, we found that adaptive behavior functioning only influenced adherence to medical treatment recommendations and not to behavioral treatment recommendations. This stands in contrast to our pilot data (Tang et al., 2012), which did not find this relationship with a much smaller sample. We found that higher levels of adaptive behavior functioning (as measured by the GAC on the ABAS-II) were correlated with decreased parental adherence to medical treatment recommendations. In fact, it predicted parental adherence above and beyond the child’s diagnosis alone. We also found that higher adaptive functioning scores on both the Conceptual domain (which measures communication skills, functional academics, and self-direction) and Practical domain (which addresses self-care, home or school living, community use, work for working-age individuals and adults, and health and safety) were related to decreased parental adherence to medical treatment recommendations. Taken all together, we are able to conclude that when a parent reports greater overall adaptive behavior skills in their child (as seen in individuals with a diagnosis of Asperger syndrome), they are less likely to properly adhere to medical treatment recommendations.
Although we predicted a relationship between increased adaptive behavior functioning and decreased parental adherence, it was surprising that this pattern only occurred in relation to medical treatment recommendations. The relationship between medical treatment adherence and adaptive behavior functioning appears to be straightforward. When a child exhibits adaptive behavior skills, which are aspects of individual behavior that have the most impact on day-to-day activities, there might be less of a perceived need to continue to medicate the child, a treatment that is costly and can have unwanted side effects. Still, it is unclear why this pattern does not hold for behavioral treatments, but categorical diagnosis does predict parental adherence for this type of treatment.

II. Family and Contextual Factors

We also examined a number of family and contextual factors. We did not find a difference in levels of adherence of parents who were married from those who were not married, which was different from the original study (Moore & Symons, 2009). These differences in findings in our study from Moore and Symons’ study is most likely due to the unclear nature in which parental adherence was coded in Moore and Symons’ study; that is, it is unclear how the authors addressed participants who did not report at least one treatment recommendation. In our analyses, we excluded all families that did not have at least one treatment recommendation as these families did not have the opportunity to follow through with treatment recommendations, and by including these families would be inaccurate representation of the respondents reporting perfect adherence to treatment recommendations.
Based on our results, individual characteristics of the child that influenced parental adherence to treatment recommendations were the child’s diagnosis, specifically a diagnosis of Asperger syndrome, and current adaptive behavior functioning. Parents of individuals diagnosed with Asperger syndrome reported poorer adherence to behavioral treatment recommendations, compared to parents of individuals diagnosed with autism. Also, parents who reported greater presentation of adaptive behavior functioning in their child exhibited poorer adherence to medical treatment recommendations, but not to behavioral treatment recommendations. It should be noted, however, that the effects were small, which suggests that a number of other factors likely affect parental adherence. The severity of current ASD symptoms, and presentation of self-injurious and repetitive behaviors did not influence parental adherence to treatment recommendations as we hypothesized.

III. Risk Factor Index

As a novel component to our study, we created a risk factor index composed of individual and familial contextual factors to identify families who would be considered at high risk for poor parental adherence to treatment recommendations. Our original risk factor index was not predictive of parental adherence to behavioral or medical treatment recommendations, either as individual components or collectively as an index. The creation of this theoretical index was difficult, given the limited amount of existing data on parental adherence to treatment recommendations for individuals with ASD.

These results suggest that when we examine individual and familial context variables independently from one another, they influence parental adherence to medical treatment recommendations, but not behavioral treatment recommendations. However,
when we collapse individual and familial factors together, we are able to better understand how these factors influence parental adherence to behavioral treatment recommendations. In sum, when prescribing different forms of treatment recommendations, professionals need to be aware of how individual and familial contextual factors will influence how parents will follow through with the treatment recommendations.

IV. Limitations

This study aimed to further understand factors that influence parental adherence to treatment recommendations for individuals diagnosed with an ASD, building upon a study that first investigated this parent behavior in the ASD population. Limitations of this study may have impacted the study’s findings. First, participants were included in the study if the total score on the SCQ Lifetime was 15 or greater. This restriction of participants reduced not only the final sample size, but it also removed families’ responses with children who may present with fewer ASD symptoms who still might have met criteria with a more detailed diagnostic process. Second, this study was conducted online. Due to the way in which the study was implemented may have detoured families who do not have access to a computer thus compromising the generalizability of the findings. Additionally, a large number of respondents did not complete the study in its entirety, which may further bias our sample toward families with greater resources (e.g., access to a computer) and greater time (e.g., only one parent employed full-time, greater social support). Third, we only studied parental adherence to treatment recommendations, and we acknowledge that parental adherence is only form of
parental involvement in recommended treatments. Further research is needed to examine individual and familial contextual factors in order to better understand the patterns of parental adherence to treatment recommendations for individuals with ASD.

V. Clinical Implications

Professionals working with families with an individual with ASD need to be aware of the influence of parental adherence on treatment outcomes and factors influencing treatment adherence. Furthermore, professionals need to be cognizant that parental adherence varies and is influenced differently depending on the type of treatment recommendation; that is, either behaviorally-based or medically-based treatment recommendations. Based on these data, it appears that the development of a risk factor index will be important to better understand ways in which adherence changes based on family constellation and characteristics, but also separate risk factor indices will need to be developed for behavioral and medical treatment recommendations based on a larger number of studies.
APPENDIX A

MOORE AND SYMONS’ ORIGINAL QUESTIONNAIRE (2009)

I. Family Information
1. Where do you live?
   - Urban
   - Suburban
   - Rural
2. Are you married?
   - Yes
   - No
3. How many children live at home?
   - One
   - Two
   - Three
   - Four or more
4. How would you describe your income level?
   - Lower class
   - Middle class
   - Upper class
5. How would you describe the level of father involvement with child with disability?
   - Lower (extensively away from home / reliant on others for child care)
   - Moderate
   - Higher (equally or more involved than mother)

II. Child Information
1. How old is your child with a disability?
2. How old was your child at their first diagnosis?
3. What is your child’s diagnosis (diagnoses)?
4. How severe are your child’s learning challenges? (if you do not know your child’s IQ, use your best estimate, or estimate from child’s doctor)
   - None
   - Mild (IQ 55-70)
   - Moderate (IQ 40 – 55)
   - Severe / Profound (IQ 20-40)
5. Please check the box in each row that best describes your view of the severity of your child’s problem behavior:

<table>
<thead>
<tr>
<th>Verbal Problem Behaviors</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
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<td>Aggression</td>
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<td>Destruction</td>
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<td>Self-injury</td>
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<tr>
<td>Other (e.g., non-compliance, running away)</td>
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</tbody>
</table>

III. Behavioral Treatments

1. What specific behavioral treatment recommendations were made in the past 12 months? (select all that apply)
   - □ Reinforcement: Praise, access to preferred things, points, tokens
   - □ Set up for good behavior: Modeling good behaviors, choices instead of demands, activity schedules, providing fun things in tough situations
   - □ Punishment: Taking privileges away, time out
   - □ Not reacting to problem behavior
   - □ Other (e.g., restraint)

2. Which treatments did you always follow through with exactly as recommended? (select all that apply)
   - □ Reinforcement: Praise, access to preferred things, points, tokens
   - □ Set up for good behavior: Modeling good behaviors, choices instead of demands, activity schedules, providing fun things in tough situations
   - □ Punishment: Taking privileges away, time out
   - □ Not reacting to problem behavior
   - □ Other (e.g., restraint)

3. Did you make any changes on your own to any behavioral treatment recommendations, apart from discussion with your provider?
   - □ Yes □ No

4. If yes, how? (select all that apply)
   - □ Used reinforcement less often or less consistently than recommended
   - □ Used set up for good behavior strategies less often or less consistently than recommended
   - □ Punished or restrained less often or consistently than recommended
   - □ Reacting to problem behavior more than recommended
IV. Medical Treatments

1. What specific medical treatment prescriptions were made for the management of problem behavior? (select all that apply)
   - [ ] Oral medication
   - [ ] Regular office visits with psychiatrist, psychologist, or M.D.
   - [ ] Exercise or other physical activity regimen
   - [ ] Modifications to diet
   - [ ] Other (specify)

2. Which medical treatment prescriptions did you always follow through with exactly as recommended? (select all that apply)
   - [ ] Oral medication
   - [ ] Regular office visits with psychiatrist, psychologist, or M.D.
   - [ ] Exercise or other physical activity regimen
   - [ ] Modifications to diet
   - [ ] Other (specify)

3. Did you make any changes on your own to medical treatment recommendations, apart from discussion with your doctor?
   - [ ] Yes  [ ] No

4. If yes, how? (select all that apply)
   - [ ] Gave medications more or less often than prescribed
   - [ ] Less consistent with office visits than prescribed
   - [ ] Less consistent with exercise or physical activity
APPENDIX B
ITEMS KEPT FROM MOORE AND SYMONS’ QUESTIONNAIRE (2009)

I. Family Information
1. Where do you live?
   □ Urban
   □ Suburban
   □ Rural

2. How many children live at home?*
   □ One
   □ Two
   □ Three
   □ Four or more

3. How would you describe the level of father involvement with child with disability?
   □ Lower (extensively away from home / reliant on others for child care)
   □ Moderate
   □ Higher (equally or more involved than mother)

II. Child Information
1. How old is your child with a disability?
2. How old was your child at their first diagnosis?
3. How severe are your child’s learning challenges? (if you do not know your child’s IQ, use your best estimate, or estimate from child’s doctor)
   □ None
   □ Mild (IQ 55-70)
   □ Moderate (IQ 40 – 55)
   □ Severe / Profound (IQ 20-40)

4. Please check the box in each row that best describes your view of the severity of your child’s problem behavior:

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* Question and/or answer was modified slightly from Moore and Symons’ Questionnaire (2009), but did not alter the integrity of the question and/or answer.
III. Behavioral Treatments
1. What specific behavioral treatment recommendations were made in the past 12 months? (select all that apply)
   □ Reinforcement: Praise, access to preferred things, points, tokens
   □ Set up for good behavior: Modeling good behaviors, choices instead of demands, activity schedules, providing fun things in tough situations
   □ Punishment: Taking privileges away, time out
   □ Not reacting to problem behavior
   □ Other (e.g., restraint)
2. Which treatments did you always follow through with exactly as recommended? (select all that apply)
   □ Reinforcement: Praise, access to preferred things, points, tokens
   □ Set up for good behavior: Modeling good behaviors, choices instead of demands, activity schedules, providing fun things in tough situations
   □ Punishment: Taking privileges away, time out
   □ Not reacting to problem behavior
   □ Other (e.g., restraint)
3. Did you make any changes on your own to any behavioral treatment recommendations, apart from discussion with your provider? □ Yes □ No
4. If yes, how? (select all that apply)
   □ Used reinforcement less often or less consistently than recommended
   □ Used set up for good behavior strategies less often or less consistently than recommended
   □ Punished or restrained less often or consistently than recommended
   □ Reacting to problem behavior more than recommended

IV. Medical Treatments
1. What specific medical treatment prescriptions were made for the management of problem behavior? (select all that apply)
   □ Oral medication
   □ Regular office visits with psychiatrist, psychologist, or M.D.
   □ Exercise or other physical activity regiment
   □ Modifications to diet
   □ Other (specify)
2. Which medical treatment prescriptions did you always follow through with exactly as recommended? (select all that apply)
   □ Oral medication
   □ Regular office visits with psychiatrist, psychologist, or M.D.
   □ Exercise or other physical activity regiment
   □ Modifications to diet
   □ Other (specify)
3. Did you make any changes on your own to medical treatment recommendations, apart from discussion with your doctor?
   □ Yes  □ No
4. If yes, how? (select all that apply)
   □ Gave medications more or less often than prescribed
   □ Less consistent with office visits than prescribed
   □ Less consistent with exercise or physical activity
APPENDIX C

ITEM REMOVED FROM MOORE AND SYMONS’ QUESTIONNAIRE (2009)

I. Family Information
   1. Are you married?
      □ Yes
      □ No
I. Family Information

1. Respondent
   □ Mother
   □ Father
   □ Other: [fill in the blank]

2. What is your current marital status?
   □ Married, living together
   □ Married, living apart
   □ Unmarried, living together
   □ Unmarried, living apart

3. Mother’s current age (in years)
   □ [fill in the blank]

4. Father’s current age (in years)
   □ Less than $15,000
   □ $15,000 - $29,999
   □ $30,000 - $49,999
   □ $50,000 - $74,999
   □ $75,000 - $99,999
   □ $100,000 or more

5. Mother currently employed?
   □ Yes
   □ No

6. Mother’s current employment status?
   □ Full time
   □ Part time

7. Number of hours mother is currently employed
   □ [fill in the blank]

8. Father currently employed?
   □ Yes
   □ No

9. Father’s current employment status?
   □ Full time
   □ Part time

10. Number of hours father is currently employed
    □ [fill in the blank]
II. Child Information

1. What is your child’s gender?
   □ Male
   □ Female

2. What is your child’s diagnosis?*
   □ Autism
   □ Autism spectrum disorder (ASD)
   □ Asperger syndrome
   □ Pervasive developmental disorder (PDD)
   □ High-functioning autism (HFA)
   □ Other: [fill in the blank]

3. What is your child’s IQ? If you do not know your child’s IQ, use your best estimate from child’s doctor.*
   □ Below average
   □ Average
   □ Above average

* Question and/or answer was modified slightly from Moore and Symons’ Questionnaire (2009), but did not alter the integrity of the question and/or answer.
I. Family Information

1. Respondent
   - Mother
   - Father
   - Other: ________________________

2. Where do you live?
   - Urban
   - Suburban
   - Rural

3. What is your current marital status?
   - Married, living together
   - Married, living apart
   - Unmarried, living together
   - Unmarried, living apart

4. Mother’s current age (in years) ____________________

5. Father’s current age (in years) ____________________

6. How many children live at home?
   - 1
   - 2
   - 3
   - 4 or more

7. How would you describe your income level?
   - Lower class
   - Middle class
   - Upper class

8. Total yearly family income
   - Less than $15,000
   - $15,000 – $29,000
   - $30,000 – $49,999
   - $50,000 – $74,999
   - $75,000 – $99,999
   - $100,000 or more

9. Mother currently employed?
   - Yes
   - No
10. Mother’s current employment status
   □ Full time
   □ Part time
11. Number of hours mother is currently employed___________________
12. Father currently employed?
   □ Yes
   □ No
13. Father’s current employment status
   □ Full time
   □ Part time
14. Number of hours father is currently employed___________________
15. How would you describe the level of father involvement with child with disability?
   □ Lower (extensively away from home/reliant on others for child care)
   □ Moderate
   □ Higher (equally or more involved than mother)
16. List all individuals living in the household with the child with a disability. Identify age in years, relationship to child with disability, and if a legal dependent.

II. Child Information
1. What is your child’s gender?
   □ Male
   □ Female
2. How old is your child with a disability (in years)?___________________
3. How old was your child at their first diagnosis (in years)?___________________
4. What is your child’s diagnosis (diagnoses)?
   □ Autism
   □ Autism spectrum disorder (ASD)
   □ Asperger syndrome
   □ Pervasive developmental disorder (PDD)
   □ High-functioning autism (HFA)
   □ Other: ____________________________
5. What is your child’s IQ? If you do not know your child’s IQ, use your best estimate or estimate from child’s doctor.
   □ Below average
   □ Average
   □ Above average
6. Please check the box in each row that best describes your view of the severity of your child’s problem behavior:

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<td>Other (e.g., non-compliance, running away)</td>
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III. Behavioral Treatments

1. What specific behavioral treatment recommendations were made in the past 12 months? (select all that apply)
   - Reinforcement: Praise, access to preferred things, points, tokens
   - Set up for good behavior: Modeling good behaviors, choices instead of demands, activity schedules, providing fun things in tough situations
   - Punishment: Taking privileges away, time out
   - Not reacting to problem behavior
   - Other (e.g., restraint): ___________________________________
   - None

2. Which treatments did you always follow through with exactly as recommended? (select all that apply)
   - Reinforcement: Praise, access to preferred things, points, tokens
   - Set up for good behavior: Modeling good behaviors, choices instead of demands, activity schedules, providing fun things in tough situations
   - Punishment: Taking privileges away, time out
   - Not reacting to problem behavior
   - Other (e.g., restraint): ___________________________________
   - None

3. Did you make any changes on your own to any behavioral treatment recommendations, apart from discussion with your provider?
   - Yes
   - No

4. If yes, how? (select all that apply)
   - Used reinforcement less often or less consistently than recommended
   - Used setup for good behavior strategies less often or less consistently than recommended
   - Punished or restrained less often or consistently than recommended
   - Reacting to problem behavior more than recommended
IV. Medical Treatments

1. What specific medical treatment prescriptions were made for the management of problem behavior? (select all that apply)
   - Oral medication
   - Regular office visits with psychiatrist, psychologist, or M.D.
   - Exercise or other physical activity regimen
   - Modification to diet
   - Other (specify): ________________________________
   - None

2. Which medical treatment prescriptions did you always follow through with exactly as recommended? (select all that apply)
   - Oral medication
   - Regular office visits with psychiatrist, psychologist, or M.D.
   - Exercise or other physical activity regimen
   - Modification to diet
   - Other (specify): ________________________________
   - None

3. Did you make any changes on your own to medical treatment recommendations, apart from discussion with your doctor?
   - Yes
   - No

4. If yes, how? (select all that apply)
   - Gave medications more or less often than prescribed
   - Less consistent with office visits than prescribed
   - Less consistent with exercise or physical activity


