

Research Paper

Examining treatment adherence among parents of children with autism spectrum disorder

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Abstract

Background: Children with Autism Spectrum Disorder (ASD) participate in a variety of treatments, including medication, behavioral, alternative and developmental treatments. Parent adherence to these treatments is crucial for positive child outcomes.

Objective: The current study: 1) Explored patterns of parent adherence across the full range of treatments that are prescribed to children with ASD and, 2) Examined whether parent demographics, parent treatment attitudes, and child ASD severity contribute to parents' adherence across ASD treatments.

Method: Questionnaires were distributed to parents of children with ASD in a southeastern state. Parents ($N = 274$) were included if they were parenting a child with ASD who was receiving treatment for ASD symptoms. Paired t -tests and multiple linear regression were used to assess the study aims.

Results: Adherence to medication treatment was significantly greater than adherence to behavioral, developmental, or alternative treatments (adjusted p -values 0.0006, 0.0030, 0.0006 respectively). Perceived family burden of a treatment was associated with lower adherence to medication, developmental, and alternative treatments. Finally, greater ASD severity was associated with lower adherence to alternative treatments.

Conclusion: Overall, the independent variables accounted for more variance in adherence to medication and alternative treatments than in behavioral and developmental treatments. Parents' adherence to ASD treatment differs significantly by treatment type and is influenced by parental perceptions of the burden of treatment on the family. These findings highlight the importance of understanding and addressing the impact of ASD treatment regimens on family life. © 2015 Elsevier Inc. All rights reserved.

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Autism spectrum disorder (ASD) is a chronic condition that impacts 1 in every 88 children.¹ ASD is a neurodevelopmental disorder characterized by impairment in (1) reciprocal social communication and interaction and (2) restricted, repetitive patterns of behavior, interests, or activities.² Many individuals with ASD also show associated symptomatology including sleep disturbances, hyperactivity, irritability, and aggression. As such, caregivers are faced with multiple treatment options, including medication, behavioral, developmental, and alternative treatments. Parent implementation is a critical component to

achieving positive outcomes from both medication and behavioral ASD interventions such as applied behavior analysis (ABA).³ Although several studies have examined effects of parent training on implementation of ASD treatment with their children^{4,5} little is known about: a) the extent to which parents adhere to treatment recommendations in the absence of professional supervision, or b) what child and parent factors may influence treatment adherence for parents of children with ASD. Given the high costs of treatments for children with ASD,⁵ efforts to assess and maximize treatment adherence are of vital importance.

Levels of treatment adherence

Treatment adherence plays a critical role in determining the effectiveness of interventions as well as the economic burden of a condition for families and society.⁵ While the

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operationalization of “adherence” in the literature has varied widely across studies, patient *non-adherence* can be broadly understood as a patient’s “incomplete implementation of instructions” issued by a provider.⁶ In the adherence literature across fields of study, meta-analysis has identified average patient non-adherence rates of 24.8% across physician-recommended treatments types,⁷ with some non-adherence rates approaching 40%.⁸ The type of treatment implemented greatly impacts treatment adherence and non-adherence, with treatment regimens involving lifestyle or behavior changes showing rates of non-adherence of up to 70%.⁹ For this reason, an understanding of treatment adherence among parents of children with ASD must account for the diverse types of treatments that families participate in, including behavioral approaches, pharmacological treatment, dietary regimens, speech and occupational therapy, and many others. It is important to examine adherence to these treatments separately since parents report using an average of seven different treatments simultaneously.¹⁰

Little is known about parents’ adherence to ASD treatments outside of controlled clinical trials. In one of the few existing studies, Moore and Symons¹¹ found that adherence to behavioral treatment recommendations was significantly lower than adherence to medication treatments among parents of children with ASD. Such reduced adherence to behavioral recommendations is likely to have substantial implications for individuals with ASD, in that their treatments frequently involve pervasive changes to parenting behaviors.^{12,13} Importantly, a second study by Moore and Symons¹⁴ found that parents reported using behavioral skills significantly less at home than when observed in the clinical setting.¹¹ The current study extended this work by examining parents’ adherence to other types of commonly prescribed treatments, including developmental and alternative treatments.

Predictors of treatment adherence

In addition to examining levels of treatment adherence, this study explored factors that contribute to parents’ adherence to medication, behavioral, developmental, and alternative ASD treatments. Because the intensity, level of complexity, and pervasiveness of parent behavior changes differ greatly between treatments, it is important to examine and compare the effect of these factors for each treatment type. Within the medical adherence literature, a number of theoretical models have been developed to identify factors impacting patient adherence to treatment.¹⁵ Yet, studies of parent adherence to pediatric treatments have tended to focus more on adherence to medication regimens for chronic conditions like asthma and HIV rather than adherence to behavioral recommendations.^{16,17} A related literature examines predictors of adherence among children and parents participating in psychotherapy for the treatment

of oppositional, aggressive, and antisocial behavior.¹⁸ Specific parent demographics that have been associated with greater adherence include older parent age, higher levels of education, and being married.^{11,19,20} Additionally, parents’ treatment attitudes, such as their confidence in the effectiveness of a treatment and lowered perception of the treatment’s burden on the family, have been found to contribute to greater treatment adherence.^{14,21,22} Finally, more severe child symptoms have shown both positive and negative associations with parent adherence.²⁰

Thus, combined medical and mental health literature suggest that parent demographics, parent treatment attitudes, and child characteristics contribute to parent treatment adherence generally. Accordingly, we might expect similar factors to contribute to parent treatment adherence for ASD.

The current study

Research with other pediatric populations demonstrates the importance of parent adherence for child outcomes, pointing to numerous predictors of parent treatment adherence. Yet, only one study to date has examined adherence among parents of children with ASD, and that study was limited in examining only two of the many treatment types used for children with ASD. The current study fills a critical gap in scientific understanding of treatment adherence among parents of children with ASD. We employed a cross-sectional survey design to explore self-reported treatment adherence among a sample of parents of children with ASD. This study has two purposes. The first is to explore patterns of self-reported parent adherence across the range of treatments that are prescribed to children with ASD. Based on previous research,¹¹ we expect that parents will report the greatest adherence to medical treatments. The second purpose is to examine the child and parent factors that contribute to parents’ self-reported adherence for each specific ASD treatment type. We expect that higher parent age and education, being married, confidence in treatment effectiveness, lower perceived family burden, and more severe child ASD symptoms will contribute to greater treatment adherence. The research has important implications for promoting parent treatment adherence and improving outcomes for children with ASD.

Methods

Procedures

We distributed a survey throughout a Southeastern state to assess parents’ self-reported adherence to ASD treatments. Parents were recruited in two ways. First, mail and electronic surveys were distributed in ASD clinics and through ASD support organizations. Second, paper surveys were mailed to current and past recipients of a

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