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Parental perspectives on attention-deficit/hyperactivity disorder treatments for children

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Abstract

This study investigated parental perspectives and experiences on the evaluation and treatment process associated with attention-deficit/hyperactivity disorder (ADHD). Five hundred sixty-eight parents of youth 2-28 years-old (M = 9.37; SD = 4.11) diagnosed with ADHD responded to a 14-item online survey about their child's diagnosis and treatment. Parents reported that they had tried an average of 4.49 interventions (SD = 2.63). Parents further shared factors in treatment selection, most helpful parenting strategies, and preferences for types of treatments and treatment targets. A majority of parents reported incorporating many non-traditional strategies (e.g., exercise, healthy eating, outdoor activities) with goals of improving their child's coping skills, study habits, and anger management. The findings show that treatment choices were often selected based on trust in the provider, research support, and the child's preference. Given parental preferences for non-traditional strategies, treatment development efforts should consider these strategies as a component of a broader multimodal treatment approach to ADHD.

Keywords

Attention-deficit/hyperactivity disorder treatment, parenting, behavioral parent training, coping skills, exercise, health, treatment targets

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Attention-deficit/hyperactivity disorder (ADHD) is a prevalent childhood disorder characterized by a persistent pattern of inattention and/or impulsivity/hyperactivity that interferes with daily functioning and development (American Academy of Pediatrics, 2001). Children with ADHD are at an increased risk of adverse outcomes in both the short-term (during childhood) and the long-term, lasting into adulthood (Hechtman et al., 2016). Throughout their schooling, children with ADHD are more likely to exhibit poorer performance in reading, writing and mathematics as well as higher rates of repeating a grade, expulsions, and suspensions (Barry et al., 2002; Biederman et al., 1996; Jensen et al., 2004; LeFever, Villers, Morrow, & Vaughn III, 2002; Loe & Feldman, 2007). During adolescence, ADHD is also associated with more legal troubles and adverse driving outcomes (e.g., accidents, speeding citations, and license suspensions) (Barkley et al., 1996). Such outcomes often persist into adulthood (Roy et al., 2019). Throughout their lifetime, those with ADHD have almost twice the rate of incarceration (Gordon & Moore, 2005). Additional negative outcomes associated with ADHD throughout development include increased rates of risky sexual behavior (Huggins et al., 2015), smoking and other substance use disorders (Lambert & Hartsough, 1998; Wilens et al., 2011), antisocial personality disorder and conduct disorder (Barkley et al., 1990), increased mortality rates (Dalsgaard, Leckman, Mortensen, Nielsen, & Simonsen, 2015) and risk of physical injury (Dalsgaard, Østergaard, Leckman, Mortensen, & Pedersen, 2015), self-inflicted harm (Barkley et al., 1990; DiScala et al., 1998; Lambert & Hartsough, 1998), and risk of suicide attempts (American Psychiatric Association, 2013). Additionally, the adverse outcomes associated with ADHD often extend beyond the child to his or her family. Parents of children with ADHD experience increased levels of stress when compared to parents of children without ADHD (Deault, 2010; Theule et al., 2010; van der Oord et al., 2006).

Stimulant medications are often the first line of treatment for ADHD (Danielson et al., 2018; Pliszka, 2007) given their efficacy in improving symptoms (Spencer et al., 1996). For example, the seminal Multimodal Treatment of ADHD (MTA) study found that ADHD symptoms were significantly reduced in children randomized to medication compared to children randomized to intensive behavioral treatment including a parent protocol (Jensen, 1999). According to a Center for Disease Control and Prevention (CDC) report, 4.3% of children in the United States in 2003 had taken a stimulant medication for ADHD (CDC, 2005) and one study found that 71% of the children diagnosed with ADHD in one school were currently prescribed a stimulant (Rowland et al., 2002). However, despite their widespread use and benefits, stimulants also have significant limitations, including side-effects, limited long-term benefits, and the potential for misuse and diversion (Rowland et al., 2002; Wilens et al., 2008). More recent work has also identified reduction in height and increase in weight and body mass index associated with long-term stimulant medication (Greenhill et al., 2020).

Fortunately, there are also many empirically-supported behavioral treatments for ADHD that involve helping parents to support their child. These types of behavioral treatments such as Parent Management Therapy, Behavioral Parent Training, and Parent-Child Interaction Therapy (PCIT) (Chronis et al., 2006; Owens et al., 2003; Zwi et al., 2011) have been shown to improve children's behavior, increase positive social development and reduce parenting stress. Efficacy for such treatments has been demonstrated for children as young as preschool. For example, ADHD symptoms diminish significantly after behavioral parent training as compared to both a parent counseling and support group and a waitlist control group (Chronis et al., 2006; Sonuga-Barke et al., 2001; Zwi et al., 2011). Further, PCIT has been beneficial to reduce symptoms of ADHD putatively through improving the parent-child relationships (Sonuga-Barke et al., 2001; Wagner & McNeil, 2008).

Despite these promising parental interventions for children with ADHD, there are areas for improvement. For example, while changes are significant, effect sizes are generally small, not sustainable over the long-term in follow-up studies, and have limited effects on core ADHD symptoms (Zwi et al., 2011). Interestingly, there is evidence to suggest that the timing of interventions may play a role in outcomes. For example, in a randomized trial of school-aged children with ADHD, treatment sequencing of behavior treatment prior to medication predicted differences in behavior outcomes (Pelham Jr. et al., 2016). Specifically, initiating treatment with behavioral parent training and later adding medication (compared to the sequence of the 2 treatments in reverse order) lead to significantly lower rates of school rule violations, disciplinary events, and parent/teacher ratings of oppositional behavior. Accordingly, the American Academy of Pediatrics guidelines (2019) recommend that the *first line* treatment for children with ADHD under 6 years old includes behavior interventions (i.e., parent training in behavior management and classroom interventions), not medication.

Given the potential benefits and limitations of both behavioral and pharmacological interventions, parents are often left with the question of how to select a treatment for their child. Parents worry about medication side-effects and may have confusion over what treatments to start first. In addition, access to treatment and availably of providers present further barriers to parental selection and initiation of treatment of ADHD for their child (Wright et al., 2015). Existing literature on how parents choose treatments for their children who have ADHD suggests that parents may be skeptical of giving their child medication for ADHD (Davis et al., 2012; McLeod et al., 2007; McLeod, Pescosolido, Takeuchi, 2004). Improvements in the child's social situation and emotional state were among the most important factors influencing treatment decisions (Fergert et al., 2014), as were treatment outcomes (Schatz et al., 2015; Waschbusch, et al., 2011). Evidence also suggests that parental socio-economic status, severity of ADHD symptoms, desired outcome of treatment, and availability of treatment all impact parent choices. However, a recent study by Fiks and colleagues (2013) demonstrated that parents may be more likely to initiate medication if their goal is to improve academic achievement (Fiks et al., 2013). Thus, parents, who are faced with an abundance of conflicting information regarding the treatment of ADHD, play a critical role in their child's outcomes as the decision-maker regarding treatment.

Although there is extant research examining parental attitudes towards ADHD medication treatment, the evidence is split between positive and negative reviews (Brinkman, Sherman, Zmitrovich, Visscher, Crosby, Phelan & Donovan, 2009; Coletti et al., 2012). Additionally, there is little known about parent attitudes towards *alternative* treatment options. This is especially important because at present, there are many other nontraditional therapeutic treatment options available to parents (albeit with varying levels of evidence). These include, but are not limited to, natural/herbal supplements, diet, exercise programs, yoga training, and meditation. Identifying such parental attitudes and preferences is important especially within the wider literature showing that patient preferences – and parental preferences for their children – are associated with improved treatment participation and outcomes (e.g., Say & Thomson, 2003; Williams et al., 2016; Nock & Kazdin, 2001). There is a need to identify and understand the factors associated with treatment preference and what treatments parents prefer and choose for their children.

To address this gap in the literature, the current study utilized a survey format to investigate two aims: (1) parent reports on the different treatments they have tried for their child, and (2) parent preferences for choosing providers, treatment strategies and the goals/skills to be incorporated into their child's treatment.

Method

We developed a 14-item survey over a 1-year collaborative process with several parents, pediatricians, and other colleagues. The survey focused on parental impressions of and experiences with the ADHD diagnostic and treatment process (see Appendix) and was administered online via Yale-secured Qualtrics. Parents were recruited through Amazon Mechanical Turk (M-Turk) for a survey about their child's ADHD (the sample was restricted to individuals within the United States). Notably, samples recruited via M-Turk are representative of the United States population. Indeed, such data were shown to be reliable and comparable to other data collected via other means (e.g., Buhrmester et al., 2011; Mason & Suri, 2012). The full survey text can be found as Appendix A. Parents reported on the survey questions about their child's diagnostic process of ADHD, the different treatments they have tried for their child and personal preferences for a variety of traditional and non-traditional ADHD treatments. Parents were given the options to endorse more than one response to some of the questions (e.g., Which skills would you want your child to learn in treatment?) and write in answers when appropriate. Additionally, for preference questions, parents were given choices based on level of importance to parents and provided their ranking of importance (e.g., What's important to you when you are choosing an intervention for your child? a) Cost of the intervention/covered by insurance: *not important, slightly important, fairly important, important, very important*). Responses to these questions were rank-ordered by parents from most important to least important. Information about the types of ADHD treatments that parents would like to seek for their children in the future was also solicited. All procedures were approved by the Yale Institutional Review Board.

Results

Demographics

Seven hundred and fifty-seven ($N = 757$) mostly parent responders provided anonymous responses to the survey in two waves. Six hundred of those ($N = 600$) reported that their children were diagnosed with ADHD. Of those, five hundred sixty-eight ($N = 568$) responses were validated and included in analyses. Surveys were invalid ($N = 32$) if data were missing or if the survey was incorrectly completed. The final sample was 56% female, 40% male (4% unknown or other) while 77% reported that they were White/Caucasian ($N = 439$), 10% Black/African American ($N = 58$), 5% Asian ($N = 31$), 1% ($N = 5$) identified as multiracial, 0.2% ($N = 1$) Native American or Alaskan Native, and 6% ($N = 34$) declined to respond.

Average age of the child was 9.37 years (SD = 4.11). The average age at ADHD diagnosis was 6.46 years (SD = 3.29), while the average age ADHD was first suspected was 5.33 (SD = 2.5). The vast majority of participants were parents (88.4%), while also including grandparents (2.6%), foster parents (0.5%), relatives (3.7%), and caregivers (4.8%). Families' economic status was primarily middle to upper-middle class, with family income reported in the following areas: <$10,000 (2.3%), $10,000–$25,000 (13.0%), $25,000–$50,000 (34.0%), $50,000–$100,000 (37.9%), >$100,000 (12.9%). The majority of children were diagnosed by their pediatricians (46.0%), followed by psychologists (18.0%), psychiatrists (11.3%), other doctors (3.3%), and teachers (3.2%; Figure 1). The primary ADHD-related problems reported by parents were poor attention (86.1%), low frustration tolerance (54.4%), impulsivity (52.5%), behavioral problems (51.8%), and hyperactivity (47.4%; Figure 2).

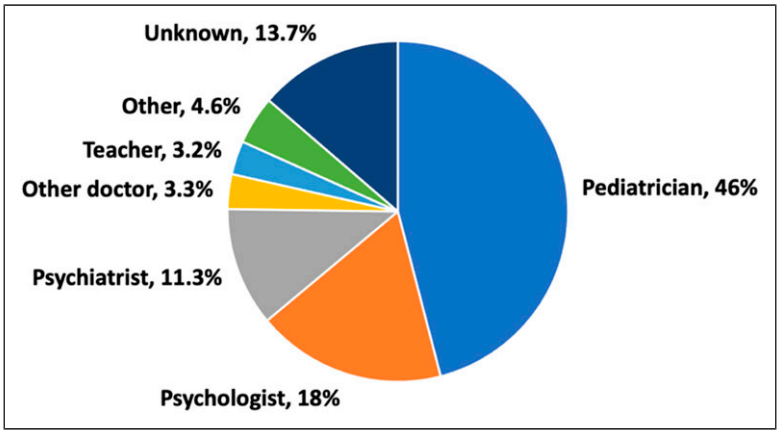

Figure 1. Who diagnosed your child?

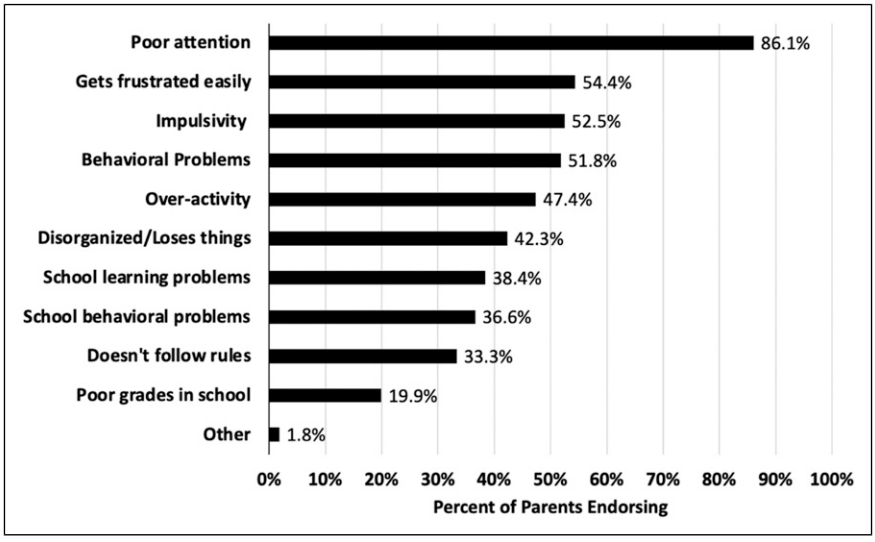

Figure 2. ADHD problems.

Treatment type

In terms of treatments used for these ADHD-related problems, parents reported implementing an average of 4.49 different interventions (SD = 2.63). The most common treatments parents reported trying were: the child meeting with a therapist (65.5%), the parent meeting with a therapist (49.5%), parent training (41.2%), skills training for the child (35.2%), vitamins (28.5%), diet modifications (26.8%), and medication (25.5%; Figure 3). In addition, 4.6% of parents had tried mindfulness and/or meditation.

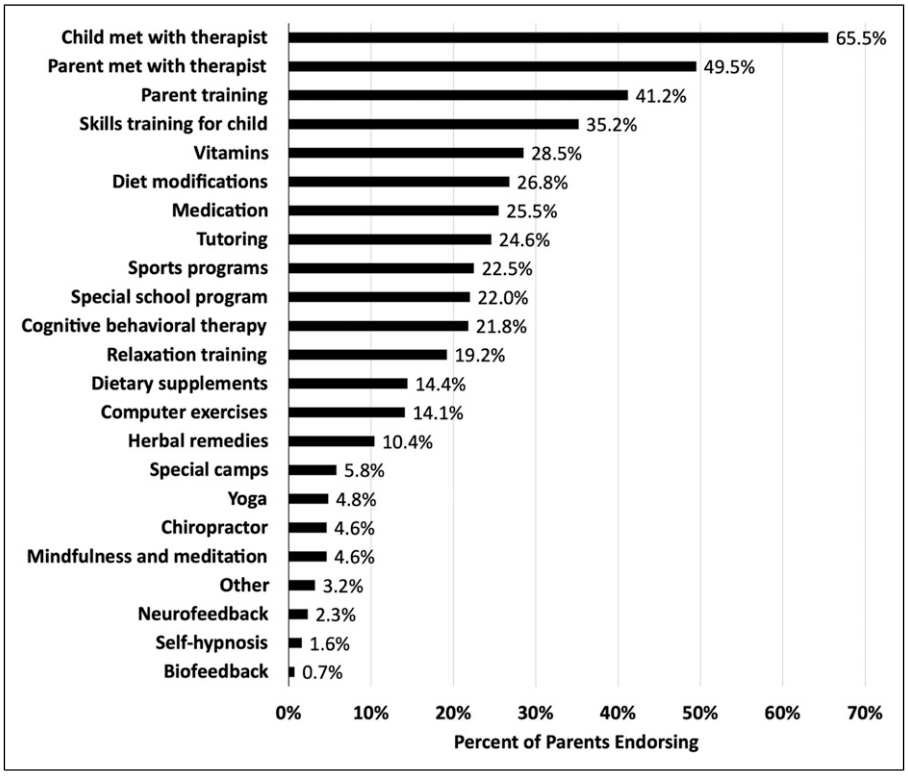

Figure 3. Interventions tried.

Parent preferences in treatment

The most important parent-rated factors in treatment selection were (in descending order): trust or comfort with the provider, research support for treatment efficacy, the child liking the intervention, doctor's recommendation, ease of intervention incorporated into my routine/lifestyle, cost of the intervention/covered by insurance, and location. Strategies that participants rated as most helpful in their parenting practices were the use of a reward system (66.7%) and praise (58.6%; Figure 4). Parents reported wanting their children to learn the following strategies in treatment: emotional coping skills (70.4%), study habits (57.9%), mood and temper management (52.5%), and time management (49.6%; Figure 5). The most common strategies that parents wanted to incorporate into their parenting included exercise (65.8%), healthy eating habits (63.2%), and outdoor activity (51.4%; Figure 6).

Discussion

These findings provide insight into caregiver perspectives of treatment utilization and treatment preferences for their children with ADHD. While the most common ADHD treatments utilized were child therapy and parent therapy, parents reported on average trying more than four of the types of interventions listed in the survey. The high rate of "Child meeting with a therapist" may reflect parents including any therapy in which the child met a therapist, including some

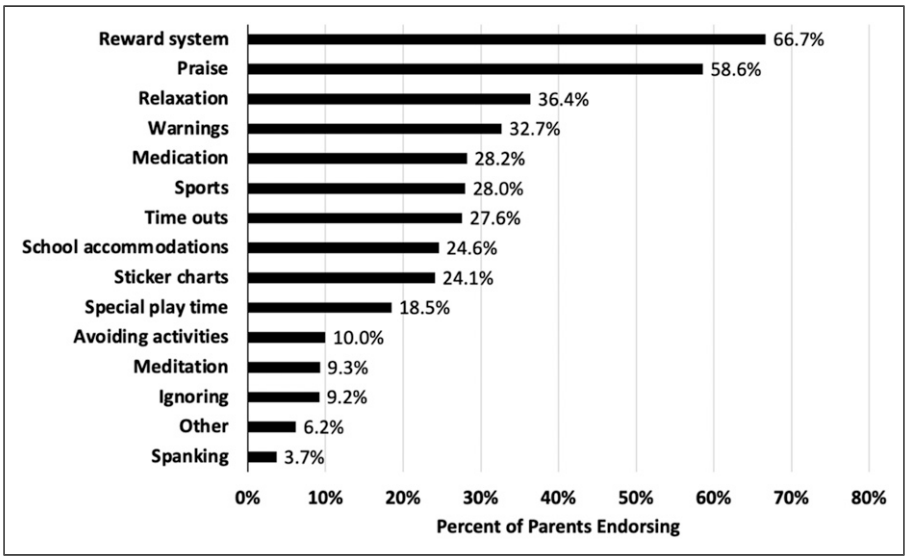

Figure 4. Helpful parenting strategies.

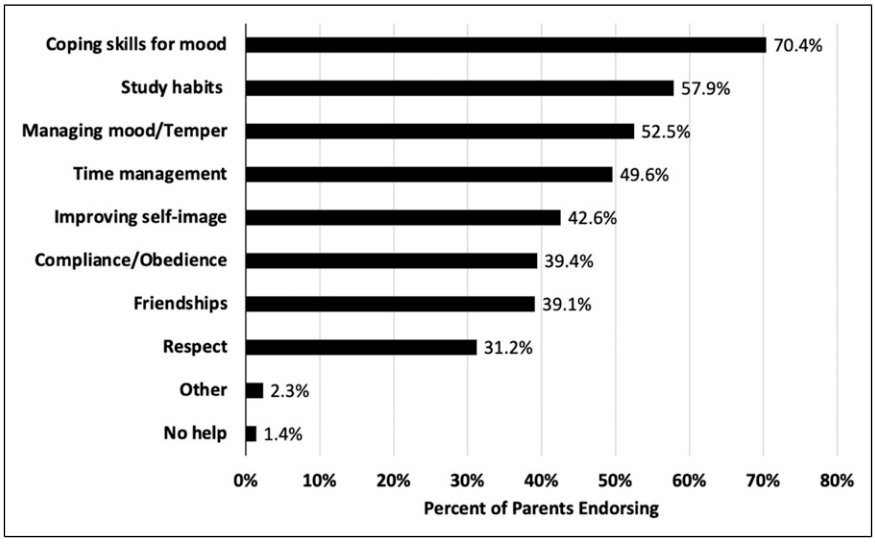

Figure 5. Strategies parents want children to learn.

psychopharmacological treatments. Interestingly, the most important factor in parents' choice of a treatment for their child was trust in the provider, followed closely by research support for the treatment. Trust in a provider/therapist is one of the key factors in treatment efficacy studies, accounting for a significant amount of variance of outcomes and relates to historical evidence about the centrality of the therapeutic relationship/alliance (Lambert & Barley, 2001). This is particularly

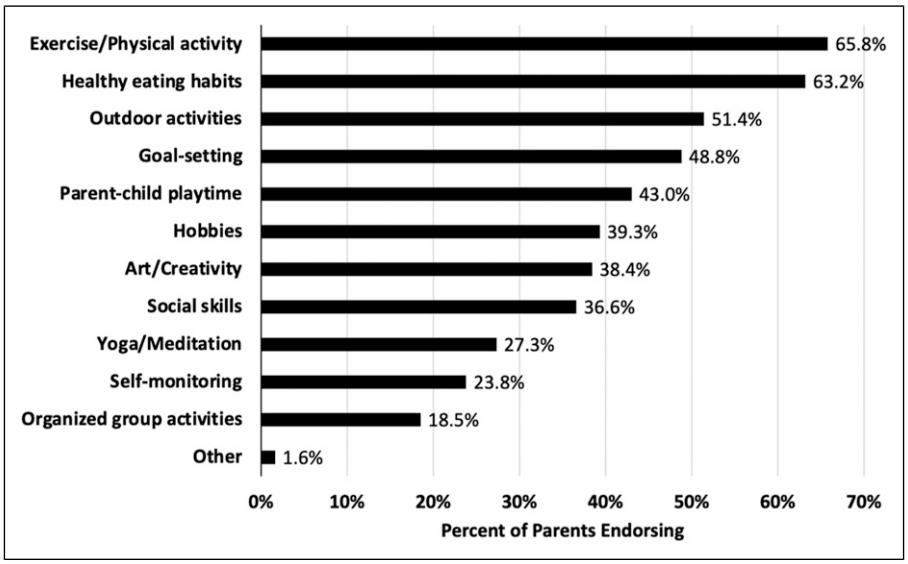

Figure 6. Strategies parents want to incorporate into parenting.

important for providers taking the time to familiarize themselves with families and build rapport prior to initiating interventions.

From the various parenting skills that are presented to parents in treatment and trainings, these findings suggest that reward systems and praise were perceived to be most helpful. This is encouraging for a few reasons. While such techniques are effective for eliciting behavior change (e.g., Rushton & Teachman, 1978), reward systems such as token economies can be one of the most complex and time-consuming intervention for parents (Soares et al., 2016). Thus, implementation of the reward systems can be a challenging task for parents. Based on this study, one important task for clinicians then may be to establish trust to help parents through such time-consuming interventions. It may also be important to help parents understand that there are often positive downstream effects of ADHD treatments for their children. Often when children are managing their behaviors and emotions more effectively and performing more successfully in school, they feel better about themselves and their mood and relationships improve.

In addition to utilizing existing treatments and parenting strategies, many parents wish other options for intervention were available. Indeed, the parents in our sample reported desire to incorporate other, more nontraditional strategies into clinical interventions. Exercise, healthy eating, and outdoor activities may be useful to incorporate into interventions based on parents' reported preferences. For instance, there is a significant literature on the value of exercise and nutrition on the well-being of children with ADHD which need to be incorporated in the readily available treatment options for families (Christiansen et al., 2019; Holtom &Nigg, 2020; Baaki et al., 2021). Further, parents expressed strong preferences for outcomes including improved child coping skills, study habits, and temper management, among others. Incorporating these treatment targets and refining existing interventions may improve treatment compliance and retention rates. Treatment dropout has consistently been a difficulty in delivering evidence-based psychosocial interventions over multiple months (Swift & Greenberg, 2014). This is particularly challenging due to the estimated rates of ADHD in parents (about 40–50%) of children with a diagnosis. Parent perceptions of

ADHD treatments may inform future efforts including developing novel interventions and increasing access to existing treatments. Parents may also be interested for their own personal benefit. Future research should examine the effect of these treatment strategies on parents diagnosed with ADHD.

It is important to note that two of the most evidence-based interventions, parent training and medication, were the third and seventh most frequently tried treatments, respectively, by the parents in this study. Notably, this is not consistent with recent national samples that suggest that medication is the primary treatment based on U.S. parent-reported usage rates (Danielson et al., 2018). Rather, it appears that parents often do not want to give ADHD medications to their children and prefer alternative methods of treatments. One possible explanation for this discrepancy is that this may reflect a difference due to our sampling methods utilizing a relatively new online Mechanical Turk sampling methodology. Alternatively, it may suggest emerging parental interest in nontraditional treatments. Our findings may further indicate that there may be a significant difference between the academic consensus and the reality in the clinical setting with regards to the preferred treatment paradigm of ADHD, one of the most prevalent childhood psychiatric disorders. Efforts should be directed to investigate possible medical and social factors that contribute to this potential dissonance. Perhaps many of the parents wanted their child to be seen and understood directly by a professional. This may provide additional strategies for emotion regulation, healthy lifestyles, social skills and organizational/planning skills. Thus, parents value their children's time and relationship with mental health and other wellness professionals. Modifications in clinicians' understanding of ADHD or efforts to further inform parents on ADHD treatments and satisfy their need to be heard and understood may be needed to resolve this issue. Additionally, it is also possible that more families in this sample may have received evidence-based behavior parent training for their child but were unaware of the name of this intervention (and thus classified it as simply, therapy).

These findings should be considered in the context of limitations. First, the sample was predominantly composed of parents, and included other caregivers. Further, the respondents were skewed toward the upper middle class socioeconomically and thus may not accurately reflect the perspectives of a national sample. Specifically, respondents in the current sample may have both the financial and medical resources available to obtain access to more treatment choices than most families nationally and internationally**.** In addition, we did not collect information about participant's ethnicity; thus, a potentially important factor may have been overlooked. Further, the sample was predominantly White/Caucasian (77%), consistent with 2019 national estimates according to the US Census Bureau (2019). Importantly, we also use M-Turk samples. Although such samples are considered representative (e.g., Buhrmester et al., 2011; Mason & Suri, 2012), future work should focus on other populations and groups to increase generalizability and reveal potential differences in preference among parents with different racial backgrounds and from random samples. The current study was also limited by the confines of a survey format and thus responses were biased to suggested forced choice options by the researchers. Respondents may have had more variability in responses if given more options.

Despite these limitations the current study highlights several relevant and important aspects of parental perspectives on ADHD diagnosis and treatment. This is the first study, to our knowledge, that examines the parent experience of and preference for traditional and non-traditional treatments of children with ADHD. Given more options in treatment, parents appear to prefer more non-traditional approaches that highlight health and more holistic approaches such as exercise and nutrition. Further, parents are interested in emotional coping, an aspect of ADHD that may be overlooked in many current treatments. Future research should continue to explore parent preferences for treatment approaches which may serve to improve treatment compliance, efficacy, and

retention, and examine racial, ethnic, and socioeconomic factors influencing preferences. Additionally, parents may be interested in the suggested treatment approaches for their own benefit or value these nontraditional approaches in their personal lives or treatment. Following up with parents with more open-ended responses or using focus groups may be useful to further understand parent preferences for the future of ADHD treatment.

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Supplemental Material

Supplemental material for this article is available online.

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