

Adhering to medication for attention-deficit/hyperactivity disorder in children

BY

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ABSTRACT

Despite the availability of well-established psychosocial and pharmacological treatments for attention-deficit/hyperactivity disorder (ADHD), it remains a disorder with substantial impact on public health and individual families. Though the rate of adherence to ADHD medication is similar to that of other pediatric chronic conditions, research with this population is more limited. The current study explored the hypothesis that recognition by caregivers of child functional impairment, and caregiver perception of the doctor's medication recommendation as "hasty" would account for statistically significant variance in adherence to ADHD medication. Fourteen caregivers of children between the ages of 6 and 12 years diagnosed with ADHD and prescribed an index medication within 6 months of recruitment participated in the current study. Measures included medication recommendation visual analog scale, Southampton ADHD Medication Behaviour and Attitudes Scale, Stimulant Adherence Measure, Vanderbilt ADHD Diagnostic Parent Rating Scale, and pharmacy data (i.e., medication possession ratios [MPR]). We found significant correlations between adherence (i.e., MPR) and the following: number of days included in the MPR, $\tau = -.41$, p (one-tailed) = .05, percent of children at Title 1 school considered low-income, $\tau = -.50$, p (two-tailed) = .07, and highest grade-level completed by participant being greater than high school, $\tau = -.41$, p (two-tailed) = .10. While the hypothesis was not supported, the relationships were in the hypothesized direction and warrant further investigation with a larger sample size. Clinicians who wish to improve adherence to ADHD medication in children may do so by working toward improving interactions between physician and caregivers (e.g., increasing shared decision-making between physician and caregivers).

Keywords: Attention-deficit disorder with hyperactivity; Medication adherence;
Treatment refusal; Health Knowledge, Attitudes, Practice

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Dedication

To my parents, Peggy Sewell and Juan Holguin.

Momma – your countless sacrifices afforded me a childhood of love, support, and stability that allowed me to wholeheartedly believe in the possibility of my success.

Daddy – making you proud, always has, and always will be one of my most favorite and cherished activities in life.

Chapter 1

Introduction

Attention-Deficit/Hyperactivity Disorder (ADHD): Diagnosis and Features

As the most common neurobehavioral disorder in childhood, ADHD is estimated to affect approximately eight percent of children in the United States (US; Merikangas et al., 2010; Pastor & Reuben, 2008; Visser, Lesesne, Perou, & Blumberg, 2007). Recent estimates indicate that a significant (i.e., 21.8%) increase in parent-reported ADHD occurred in the US between 2003 and 2007 (Visser, Bitsko, Danielson, Perou, & Blumberg, 2010). More than five million children in the US are estimated to have ADHD (Bloom, Cohen, & Freeman, 2010; Visser et al., 2010). Every classroom in the US is likely to have at least one student with ADHD (Hoza, 2007; Millichap, 2010). Likewise, ADHD is a common referral concern in primary care settings (American Academy of Pediatrics [AAP], 2011).

ADHD is characterized by pervasive (i.e., not episodic) developmentally inappropriate symptoms of hyperactivity-impulsivity (HI) and/or inattention (American Psychiatric Association [APA], 2000). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) the following criteria must be met in order to receive a diagnosis of ADHD: (a) symptoms of HI and/or inattention with associated impairment are present prior to seven years of age; (b) these symptoms cause impairment in at least two settings (e.g., school, home); (c) clinically significant impairment is present in social, academic, or occupational functioning; and (d) the symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder (PDD), Schizophrenia, or other Psychotic Disorder, and are not better accounted for by another mental disorder (APA, 2000). The DSM-IV recognizes three ADHD subtypes: (a) Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type (ADHD-I; 314.00) – assigned when six (or more) symptoms of inattention are present for at least six months with

fewer than six symptoms of HI; (b) Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type (ADHD-HI; 314.01) – assigned when six (or more) symptoms of HI are present for at least six months with fewer than six symptoms of inattention; and (c) Attention-Deficit/Hyperactivity Disorder, Combined Type (ADHD-C; 314.01) – assigned when six or more symptoms of both inattention and HI are present for at least six months (see Table 1 for list of symptoms). ADHD-C is the most commonly diagnosed subtype with 50 to 60% of children with this presentation, followed by 30 to 40% with ADHD-I, and approximately 10% with ADHD-HI (AAP and National Initiative for Children’s Healthcare Quality [NICHQ], 2002).

Table 1. *Diagnostic and Statistical Manual (DSM-IV) Criteria for Attention-Deficit/Hyperactivity Disorder (ADHD)*

A. Either (1) or (2):

- (1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention

- (a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- (b) often has difficulty sustaining attention in tasks or play activities
- (c) often does not seem to listen when spoken to directly
- (d) often does not follow through on instructions and fails to finish school work, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)
- (e) often has difficulty organizing tasks and activities
- (f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- (g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)
- (h) is often easily distracted by extraneous stimuli
- (i) is often forgetful in daily activities

Table 1 Continued. *Diagnostic and Statistical Manual (DSM-IV) Criteria for Attention-Deficit/Hyperactivity Disorder (ADHD)*

(2) six (or more) of the following symptoms of **hyperactivity-impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

- (a) often fidgets with hands or feet or squirms in seat
- (b) often leaves seat in classroom or in other situations in which remaining seated is expected
- (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- (d) often has difficulty playing or engaging in leisure activities quietly
- (e) is often "on the go" or often acts as if "driven by a motor"
- (f) often talks excessively

Impulsivity

- (g) often blurts out answers before questions have been completed
- (h) often has difficulty awaiting turn
- (i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Gender. Male-to-female ratios range from 2:1 to 9:1 (APA, 2000). High ratios are reported when based on clinical as opposed to community samples (APA, 2000). Girls are more likely than boys to have ADHD-I (Biederman et al., 2002). Boys with ADHD are more likely than girls with ADHD to exhibit rule-breaking and externalizing behavior problems (Abikoff et al., 2002). A study utilizing structural equation modeling further examined this association and

concluded the pathway between gender and rule-breaking is mediated by HI symptoms (Vitulano, Fite, Wimsatt, Rathert, & Hatmaker, 2012).

When study recruitment is not contingent on clinic referral, but rather occurs in the community, data indicate there are no differences in clinical correlates (e.g., psychosocial functioning) between boys and girls with ADHD (Biederman et al., 2005). Explanations for this finding vary. Some suggest clinicians' inappropriate use of heuristics may contribute to over-diagnosis of ADHD in boys (Bruchmüller, Margraf, & Schneider, 2012). Teacher ratings of boys and girls with ADHD indicate teachers tend to rate boys as more impaired than girls (Gershon, 2002). Disruptive behavior is likely recognized upon school entry. However, clinically significant inattention, which is more common in girls, may not be recognized until late childhood (APA, 2000; Millichap, 2010). Overall, symptoms of inattention are less likely to elicit a referral for services than are disruptive behaviors related to symptoms of HI (Biederman et al., 2005; Gershon, 2002). Thus, the evidence regarding the role of gender on symptoms and outcomes in ADHD is equivocal and likely biased by referral practices.

ICD-10. Prevalence of ADHD using DSM-IV criteria is expected to be higher than with the ICD-10 for several reasons (Polanczyk, Silva de Lima, Horta, Biederman, & Rohde, 2007). First, the ICD-10 requires a minimum number of symptoms from each of three dimensions (inattention, overactivity, and impulsivity) be present for a diagnosis (World Health Organization [WHO], 1993). The DSM-IV classifies HI symptoms together to form one dimension and permits a diagnosis with a minimum number of symptoms present in only one dimension. Second, the ICD-10 requires all diagnostic criteria be met in two or more different contexts (e.g., home and school). The DSM-IV is less stringent requiring only some degree of impairment be

present in two or more settings. Third, the ICD-10 identifies mood, anxiety, and developmental disorders as exclusions. The DSM-IV allows mood and anxiety to be comorbid with ADHD.

Comorbidity. Several disorders are commonly comorbid with ADHD. In fact, it is more likely than not that a child with ADHD will have a second psychiatric diagnosis (Ollendick, Jarrett, Grills-Taquechel, Hovey, & Wolff, 2008). Using DSM-IV criteria, approximately 50% of children referred for ADHD also have oppositional defiant disorder (ODD) or conduct disorder (CD) (APA, 2000). In general, ADHD and comorbid CD is associated with poorer outcomes relative to children without CD (Biederman, Newcorn, & Sprich, 1991).

Comorbid mood disorders are also associated with greater impairment in psychosocial functioning and possibly greater risk for suicidality than in children with ADHD and no mood disorder (Biederman et al., 1992; Biederman et al., 1991). Meta-analysis and longitudinal studies indicate that youth with ADHD have increased risk for major depression (Angold & Costello, 1993; Biederman et al., 1992; Biederman et al., 2008; Chronis-Tuscan et al., 2010). Initial studies indicate that adverse life events dependent on the child's behavior (e.g., poor grades, interpersonal conflict) occur more frequently in youth with ADHD and should be a target of intervention to address risk of comorbid major depression (Daviss & Diler, 2012).

Approximately 25% of children with ADHD are also diagnosed with an anxiety disorder (Biederman et al., 1992; Biederman et al., 1991). This figure may underestimate the prevalence of ADHD and comorbid anxiety disorders because anxiety is often overlooked in hyperactive children (Spencer, Biederman, & Mick, 2007). Findings of a longitudinal study indicate children with ADHD and a comorbid anxiety disorder experience greater psychosocial impairment, psychiatric treatment, and family history of anxiety disorders (Biederman et al., 1996).

Approximately 60% of individuals who are referred for Tourette's Disorder (TD) also have ADHD (Biederman et al., 1991; Freeman et al., 2000). Most people with ADHD do not have TD. However, when these disorders are comorbid, ADHD onset tends to precede TD (APA, 2000). Data indicate tic disorders and ADHD are distinct disorders with different presentations over time; ADHD is less likely to remit over time (Biederman et al., 1996; Spencer et al., 1999). Initial evidence suggesting stimulant medication may exacerbate tics led to limited use of this medication class to treat ADHD (Wigal, 2009). More recent evidence indicates the impairment associated with untreated ADHD supercedes that of tic disorders and use of stimulant medications for children with ADHD and comorbid TD is no longer contraindicated (Pringsheim & Steeves, 2011). Furthermore, evidence of the efficacy of alternative pharmacotherapy interventions suggest greater benefits relative to costs of treating ADHD in individuals with comorbid tic disorders (Allen et al., 2005; Pringsheim & Steeves, 2011; Tourette Syndrome Study Group, 2002)

Revisions for DSM-5. Based on available evidence, the ADHD and Disruptive Behavior Disorders Workgroup of APA made several revisions for ADHD in DSM-5 (APA, 2013). First, ADHD is included in the new diagnostic category of Neurodevelopmental Disorders. Second, there is a change in the requirement for the onset of impairing symptoms by age seven to onset of symptoms (i.e., presence, not necessarily impairment) by age 12. This recommendation is based on a systematic literature review that concluded altering the onset criterion would maintain ADHD as having childhood onset, while reducing the number of false negatives (i.e., individuals with ADHD who do not meet criteria by age seven) (Keiling et al., 2010). Third, the three subtypes described previously are three current presentations. This recommendation addresses concerns regarding the validity of the DSM-IV subtypes and is based on a literature review and

meta-analysis conducted by Willcutt and colleagues (2012). The authors conclude that available longitudinal data do not support the current use of ADHD subtypes as representing distinct groups of individuals with stable differences. Fourth, DSM-5 includes examples of inattentive and HI symptoms that are relevant to individuals with ADHD across the lifespan. Fifth, PDD is removed from the exclusion criteria. This recommendation is based on evidence that ADHD symptoms are commonly present in individuals with PDD (Coghill & Seth, 2011; Frazier et al., 2001; Goldstein & Schwebach, 2004; Simonoff et al., 2008). Thus, both diagnoses must be made accurately in order to receive effective treatment for each. Sixth, the recommendation that data be obtained from multiple informants (e.g., parent, teacher) is emphasized. This is currently identified in best-practice guidelines for assessment of ADHD, but may be overlooked by clinicians (Coghill & Seth, 2011; Valo & Tannock, 2010). Seventh, DSM-5 includes a specifier for current severity: mild, moderate, or severe.

Negative Consequences of ADHD

Childhood ADHD has an array of negative consequences such as impaired academic and peer functioning, decreased quality of life (QOL), increased likelihood of engaging in risky behaviors, and high economic burden. Impaired functioning often persists into adulthood (Klein et al., 2012). While long-term outcomes in those who receive ADHD treatment are favorable to those who do not, they do not reach levels of individuals without ADHD (Shaw et al., 2012).

Academic functioning. Overall, ADHD is associated with impairment in academic functioning. Studies find that children with ADHD score significantly lower on standardized tests of reading/language, mathematics, and written language relative to controls (Barbarelli et al., 2006; Massetti et al., 2008; McConaughy, Volpe, Antshel, Gordon, & Eiraldi, 2011). Frazier, Youngstrom, Glutting, & Watkins (2007) conducted a meta-analysis of 72 studies

published from 1990 to 2005 examining academic underachievement associated with ADHD. Results indicated a medium effect of ADHD on overall levels of achievement ($d = .71$, $z = 12.28$, $p = .001$). Effect sizes for individual content areas (i.e., reading, mathematics, and spelling) were also statistically significant and of medium size. Results of longitudinal studies indicate these poor academic outcomes persist into adolescence and young adulthood (Loe & Feldman, 2007). Additional differences between children with ADHD and controls include higher likelihood of receiving special education, retaining a grade, being suspended or expelled, and dropping out before high school graduation (Barbarese et al., 2006; Jensen et al., 2004; LeFever, Villers, Morrow, & Vaughn, 2002).

Peer functioning. In a review of the literature on peer relationships of children with ADHD, Hoza (2007) emphasized the impact of core symptoms of ADHD (i.e., HI and inattention) in developing and maintaining detrimental relationships with peers. Research involving clinical samples of children with ADHD is limited (Hoza, 2007). However, the literature consistently supports the following: (a) both boys and girls with ADHD demonstrate impairment in peer functioning; (b) a peer-initiated label of “ADHD” is associated with peer rejection; and (c) it is difficult to ameliorate the problematic peer relationships of children with ADHD (Hoza, 2007; Murray-Close et al., 2010; Nijmeijer et al., 2008).

Difficulties in peer functioning for children with ADHD are often discussed in terms of inappropriate levels of negative behavior and deficits in performance and skills (Wheeler & Carlson, 1994). A longitudinal study conducted by Bagwell, Molina, Pelham, & Hoza (2001) followed 111 children with and 100 children without ADHD for five years into adolescence. According to parent report, children with ADHD had greater peer rejection and fewer close

friendships relative to the non-ADHD group. Effects of ADHD on peer functioning were marked in participants with ADHD or CD in adolescence.

Hoza and colleagues (2005) conducted a study using peer sociometric methods to evaluate the peer relationships of 165 children with ADHD enrolled in the Multimodal Treatment of ADHD (MTA) study, and randomly selected non-ADHD comparison children matched by sex and classroom. After controlling for comorbid ODD/CD and anxiety, results indicated MTA children had significantly impaired peer relationships compared to children without ADHD on several indicators (e.g., fewer dyadic friendships, lower social preference). Of note, children with ADHD demonstrated poor peer functioning regardless of MTA treatment group assignment and despite improvement in other domains such as ADHD symptoms. This result is not surprising in light of evidence that the efficacy of interventions for peer problems of children with ADHD is limited (Mrug, Hoza, & Gerdes, 2001).

QOL. The WHO describes QOL as “the individuals perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (WHOQOL Group; 1995, p. 1405). In contrast to health status and functional impairment, QOL is subjective and essentially a patient-reported outcome (Coghill, Danckaerts, Sonuga-Barke, Sergeant, & The ADHD European Guidelines Group, 2009). While several generic QOL measures exist, three have been rigorously studied in child and adolescent mental health (Coghill et al., 2009): (a) Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1999); (b) Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Kurtin, 2001); and (c) Child Health and Illness Profile (CHIP; Riley et al., 2004a, 2004b). Two measures specific to ADHD may prove useful in treatment outcome, but are currently in

initial phases of development: (a) Weiss Functional Impairment Scale (Weiss & Brooks, 2007); and (b) ADHD Impact Module (Landgraf, Rich, & Rappoport, 2002).

Danckaerts et al. (2010) conducted a systematic review of 36 QOL studies in youth with ADHD. Results suggested the overall impact of ADHD on QOL is commensurate with that of chronic physical illnesses as well as other mental health conditions. The most substantial negative impact appeared to be in psychosocial domains, particularly achievement and family functioning.

Despite recognition that patient self-report is essential when evaluating QOL (Coghill et al., 2009; Matza, Swensen, Flood, Secnik, & Leidy, 2004), the authors reported only seven of 36 studies included patient self-report ratings. Agreement between children and their parents was greater for physical ($r_s = 0.60$ to 0.75) than psychosocial subscales ($r_s = 0.40$ to 0.48). In general, children rated their own QOL higher than their parents and may not view their QOL as impaired in comparison to healthy controls. The authors cited the positive illusory bias as a possible influence for this result. The positive illusory bias suggests individuals overestimate their abilities across domains (e.g., academic, social) in spite of established functional impairment (Owens, Goldfine, Evanelista, Hoza, & Kaiser, 2007).

Overall, Danckaerts and colleagues (2010) reported a significant negative correlation between QOL and ADHD symptoms. Thus, evidence suggested these constructs are connected, but discrete and both are required for a comprehensive understanding of a child's functioning. The authors further discussed the evidence that QOL improves following treatment. However, they emphasized that the majority of studies have examined only the medication atomoxetine (Strattera) and rely on parent-proxy report.

Coghill (2010) conducted a systematic review specifically investigating the effect of medications on QOL in ADHD. The author concluded that children with ADHD generally report QOL one-and-a-half to two standard deviations below population norms, which is similar to children with chronic physical illnesses. He further observes that side effects associated with ADHD medications (e.g., stomach pain, headache) are likely to negatively impact QOL particularly in the physical health domain. While available studies are limited, the current literature supports a favorable short-term impact of medication on QOL in ADHD. This effect is similar to that of medication on ADHD symptoms, but with smaller effect sizes.

High-risk behavior. Studies suggest that ADHD is associated with increased delinquency, alcohol and substance use or abuse, risky sexual behaviors, and unsafe driving. Molina and colleagues (2007a) reported that MTA children engaged in significantly higher rates of delinquency compared to a local normative comparison group at 36 months after MTA randomization (27.1% vs. 7.4%; $p < .001$). While studies are generally consistent in the finding that childhood ADHD increases the likelihood of delinquent behavior in adolescence or adulthood, it is unclear whether this is a direct effect of ADHD or its association with other common comorbid disruptive behavior disorders (e.g., ODD, CD) (von Polier, Vloet, & Herpertz-Dahlmann, 2012). Findings from the Pittsburgh ADHD Longitudinal Study (PALS) suggested that irrespective of comorbidity, all children with ADHD are at higher-risk for engaging in delinquent behavior (Sibley et al., 2011). Nevertheless, boys with ADHD and comorbid CD were at greatest risk of delinquency. In contrast, Satterfield and colleagues (2007) reported that boys diagnosed with hyperactivity, but not conduct problems, did not demonstrate increased risk for engaging in criminal behavior in adulthood.

Molina, Pelham, Gnagy, Thompson, & Marshal (2007b) also reported MTA children had significantly higher rates of substance use compared to a local normative comparison group. Similarly, a second study involving adolescents or young adults from PALS found elevated indicators of alcohol use among some (i.e., 15 to 17-year-olds), but not all, age groups with ADHD (Molina et al., 2007b). Charach, Yeung, Climans, & Lillie (2011) conducted a meta-analysis of 13 prospective cohort studies. Findings indicated that childhood ADHD significantly increases the risk of nicotine use in adolescence, and alcohol use disorders in young adulthood. The independent contribution of childhood ADHD (i.e., without comorbid disorders) to increased risk of substance use disorders later in life is equivocal (e.g., Brook, Brook, Zhang, & Koppel, 2010; Wilens et al., 2011).

Initial evidence suggests childhood ADHD is associated with various indicators of risky sexual behavior in young adulthood. As part of PALS, self-reported risky sexual behaviors of men ages 18 to 26 years ($n = 175$) with childhood ADHD were compared to that of men with similar demographics and no ADHD ($n = 111$) (Flory, Molina, Pelham, Gnagy, & Smith, 2006). Men with childhood ADHD reported more sexual partners, casual sex, and partner pregnancies, and younger age of initiation of sexual activity and intercourse. This finding remained after accounting for childhood conduct problems.

In a second study including participants from PALS, adolescents and young adults with childhood ADHD ($n = 203$) and controls ($n = 152$) completed the Young Adult Driving Questionnaire (Thompson, Molina, Pelham, & Gnagy, 2007). Findings indicated that presence of childhood ADHD is associated with increased risky driving in adolescence and young adulthood. Specifically, participants with ADHD had significantly higher number of accidents and tickets in the last six months as well as number of lifetime tickets. Adolescents and young

adults with childhood ADHD were more likely than controls to ever have driven without a license. HI at follow-up was found to be a significant mediator of tickets and accidents. In light of risky driving behavior by adolescents with ADHD, the AAP recommends physicians take care to prescribe ADHD medication that remains active during prime driving hours (AAP, 2011).

Economic burden. Overall, childhood ADHD is associated with substantial economic burden and subsequent public health importance (Pelham, Foster, & Robb, 2007). Based on a small number of published studies, Pelham et al. (2007) estimated the annual cost of illness (COI) of ADHD to be \$14,576 per child. The authors noted that using a conservative prevalence of 5%, the overall COI of ADHD would be \$42.5 billion for school-aged children in the US. ADHD is a unique chronic condition in that its COI is shared by individual families, as well as the education and health care systems (Pelham et al., 2007). To date, no studies detailing the cost of ADHD to families (e.g., loss of parent work productivity) have been published.

Based on data from PALS, Robb et al. (2011) reported the annual cost of educating a student with ADHD to be significantly higher than students in the comparison group (\$5,007 versus \$318). Pelham et al. (2007) estimated costs associated with crime and delinquency in ADHD to be \$7040 per year. The authors did not identify any studies reporting the costs associated with alcohol or drug abuse in ADHD. Considering the costs for pharmacological and psychosocial mental health treatment for ADHD as well as costs associated with other health services for children with ADHD, yearly cost to the health care system for one child is estimated to be \$2636 (Pelham et al., 2007). Costs associated with children with ADHD and comorbid disorders are likely greater than that of ADHD alone (Jones, Foster, & Conduct Problems Prevention Research Group, 2009).

ADHD: Assessment and Treatment

Evidence-based assessment (EBA) of ADHD. The etiology of ADHD remains largely unknown (APA, 2000). No medical test exists to accurately and reliably diagnose ADHD (APA, 2000). As such, use of EBA of ADHD is paramount (Pelham, Fabiano, & Massetti, 2005). A primary goal of EBA of ADHD is to determine whether a child's behavior sufficiently deviates from typical or developmentally appropriate behavior as to warrant a diagnosis (Pelham et al., 2005). This requires data based on behavioral observations made by parents and teachers (AAP, 2011). Pelham and colleagues (2005) described parent and teacher rating scales as the "sine qua non" for diagnosing ADHD (p. 462). This endorsement is consistent with practice parameters from The American Academy of Child and Adolescent Psychiatry (AACAP). The AACAP has established guidelines for the assessment of ADHD in children and adolescents (AACAP Work Group on Quality Issues, 2007).

Among recommendations outlined by the AACAP is the use of both broadband and narrowband rating scales to screen and assess for symptoms of ADHD and associated level of impairment. Commonly used broadband measures with good reliability and validity include the Child Behavior Checklist (CBCL, Achenbach & Rescorla, 2001) and Behavior Assessment System for Children, Second Edition (BASC-2, Reynolds & Kamphaus, 2004). Narrowband rating scales are based on the DSM-IV criteria for ADHD. Commonly used narrowband measures with good reliability and validity include the ADHD Rating Scale-IV Home and School Versions (Dupaul, Power, Anastopoulos, & Reid, 1998) and the Vanderbilt ADHD Diagnostic Parent and Teacher Scales (Wolraich, Lambert, Bickman, Simmons, Doffing, & Worley, 2004).

A clear description and understanding of the strengths and limitations of specific ADHD rating scales is useful when selecting a measure (see Collett, Ohan, & Myers, 2003 for a

comprehensive review). EBA of ADHD further necessitates careful inquiry of psychosocial impairment commonly present in children with ADHD – family functioning, peer relationships, and academic functioning (Fabiano et al., 2006; Pelham et al., 2005).

Evidence-based treatment of ADHD. Pharmacological intervention for ADHD has long been established as efficacious (Pelham, Wheeler, & Chronis, 1998). FDA-approved medications for the treatment of childhood ADHD include various central nervous system (CNS) stimulants, and one selective norepinephrine reuptake inhibitor (National Institute of Mental Health [NIMH], 2010). The MTA study directly evaluated the efficacy of four treatment modes: (a) medication management only; (b) behavioral intervention only; (c) a combination of both; and (d) routine community care. The MTA was a large multisite study including 579 children ages seven to nine years diagnosed with ADHD. Primary results were reported including a 14-month follow-up (MTA Cooperative Group, 1999).

Combination treatment and medication management alone both resulted in significantly fewer ADHD symptoms at 14-month follow-up than behavioral treatment alone or routine community care. Children who received combination treatment exhibited superior functioning (e.g., academic performance, social skills) than those assigned to other intervention conditions. Likewise, children in the combined treatment condition had lower doses of medication than those in the medication management alone condition. This finding is important because side effects from stimulant medications (e.g., sleep problems, loss of appetite) are dose-dependent (NIMH, 2010).

These findings suggest a combination of pharmacological and behavioral interventions are indicated for an evidence-based approach to treatment for ADHD. Pelham & Fabiano (2008) conducted a review of ADHD intervention studies published between January 1997 and

September 2006 (see Pelham et al., 1998 for a review of studies published prior to 1997).

Behavioral parent training, behavioral classroom management, and behavioral interventions implemented in peer group/recreational settings are classified as well-established interventions according to criteria designated by the Task Force on Promotion and Dissemination of Psychological Procedures (1995).

Behavioral parent training often takes place in a group setting over eight to 16 sessions. Characteristics common to behavioral parent training include: (a) psychoeducation about ADHD; (b) strategies for attending to and increasing appropriate child behaviors as well as consequences for problematic behaviors; and (c) methods to provide structure to the home environment as well as establish clear expectations (Barkley, 1997; Hoza, Kaiser, & Hurt, 2007; McMahon & Forehand, 2003). Skills of effective behavioral classroom management are similar to those of behavioral parent training with teachers in the classroom setting.

Daily Report Cards (DRCs) are an important addition to a behavioral classroom management intervention. Use of a DRC intervention involves teachers evaluating children on identified target behaviors in the school setting (e.g., talking without permission) and providing daily feedback to parents. Parents then enact contingencies at home based on the child's performance in school. Parents learn to establish reasonable goals, and to develop and maintain a home-based reward system (AAP & NICHQ, 2002). DRCs have substantial efficacy (Pelham & Fabiano, 2008).

Behavioral interventions implemented in peer group/recreational settings often include summer treatment programs (STPs). The Pelham STP is an intensive summer day program that provides behavioral intervention using a point system with reward and response-cost components, sport skills training, academic programs, and social skills training (Pelham & Hoza,

1996). Traditional social-skills groups conducted weekly (i.e., not an intensive summer day program) are not an evidence-based intervention for ADHD (Pelham & Fabiano, 2008).

Likewise, Pelham & Fabiano (2008) found no support for the use of nonbehavioral psychotherapeutic interventions or cognitive-behavioral therapy for treatment of ADHD.

Given the high prevalence of ADHD and the corresponding number of children that seek treatment in various settings, a number of professional organizations have established clinical practice guidelines to assist members in providing evidence-based treatment. The American Medical Association (AMA) guideline emphasizes that treatment for ADHD generally includes pharmacotherapy and adjunctive behavioral interventions with occasional supportive psychotherapy with the child and/or family (Goldman, Genel, Bezman, & Slanetz, 1998). The AAP established recommendations based on age of the child (AAP, 2011). The first line of treatment for preschool-aged children (i.e., four to five years) is evidence-based behavior therapy administered by parents and/or teachers. If the child continues to experience moderate-to-severe disturbances in functioning, the clinician may consider prescribing methylphenidate. Preferable intervention for elementary school-aged children (i.e., six to 11 years) is FDA-approved medications for ADHD and evidence-based behavior therapy administered by parent and/or teacher. Intervention recommendations for adolescents are similar with additional emphasis on obtaining the adolescent's assent to medication. An APA task force (2006) concluded the evidence-base for CNS stimulants, behavioral interventions, and the combination of the two is unequivocal in the short-term. However, current data did not support long-term use (i.e., greater than two to three years) of CNS stimulants.

Treatment Adherence: Definitions and Considerations

The WHO defines adherence as “the extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider” (2003, p. 16). This definition highlights several important characteristics of adherence. First, adherence is not dichotomous (e.g., good or bad, adherent or nonadherent), and should be assessed using continuous measures (DiMatteo, Giordani, Lepper, & Croghan, 2002; Dirks & Kinsman, 1982; La Greca, 1990; Rapoff, 2010; Rudd et al., 1989). Second, adherence must be explicitly defined based on specific behaviors as prescribed for a particular regimen (Rand & Wise, 1994; Rudd, 1993). Third, adherence measures agreement between a patient’s prescribed behavior and actual behavior (Rapoff, 2010). This may take several forms (Farmer, 1999; Dunbar-Jacob & Schlenk, 2001; Horne, 2006). Fourth, consistent with a patient-centered approach to adherence, patients are encouraged to participate in the decision-making process to determine an agreed upon treatment regimen (Adams, Dreyer, Dinakar, & Portnoy, 2004).

Some investigators differentiate between unintentional and volitional nonadherence (Adams et al., 2004; Bauman, 2000; Graves, Adams, Bender, Simon, & Portnoy, 2007). The proposed distinction is that volitional nonadherence represents a rational decision or choice not to comply with provider recommendations (Bauman, 2000). Volitional or intentional nonadherence has been defined as actively reducing, missing, or changing medication doses to be more consistent with the needs identified by the patient and/or patient’s family (Wroe, 2002). This definition emphasizes that from a patient-centered perspective, as opposed to physician as expert (Charles, Gafni, & Whelan, 1997; Charles, Gafni, & Whelan, 1999), volitional nonadherence may be adaptive (Deaton, 1985). While the distinction between volitional and nonvolitional nonadherence is an interesting one, it has proven difficult to study because it is

unclear how to accurately determine a person's intention in following or not following a particular medical regimen (Rapoff, 2010).

Standard criteria for determining adherence versus nonadherence are yet to be established. The convention in the field has been to consider participants/patients who take 80% or more of their prescribed medications to be "adherent" (Rapoff, 2010). This cutoff is based on data from an adherence-promotion intervention that adult participants who took at least 80% of their hypertension medications experienced a decrease in blood pressure (Haynes et al., 1976). While this finding has implications for hypertension, its applicability to other diseases is questionable (Rapoff, 2010). Treatment threshold effects – the amount of adherence necessary to achieve a positive effect of medical treatment – are rarely studied (Rapoff, 2010). As such, the treatment threshold effect for most chronic medical and mental illnesses remains unknown (Epstein & Cluss, 1982; Rapoff, 2010). This is true for ADHD even though initial evidence suggests possession of a stimulant medication on at least 70% of days in an academic marking period is associated with a statistically significant, but not clinically meaningful, improvement in grade point average (Marcus & Durkin, 2011).

Poor adherence is a prevalent and clinically significant concern (Matsui, 2000). Health professionals are in need of valid and reliable measures of their patients' adherence to treatment regimens (Hughes, 2007; Modi et al., 2006). While methods for assessing adherence are developing, there is currently no consensus in the literature regarding whether a gold standard of assessment exists (Cramer, 1995; Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008; Rapoff, 2010; WHO, 2003). Current methods of assessment include drug assays, observation, electronic monitors, pill counts, provider estimates, and patient/parental reports. Each method possesses specific assets and liabilities that professionals should consider when selecting a

measure of adherence (see Quittner et al., 2008 and Rapoff, 2010 for detailed reviews). The current recommendation is to include at least two methods of assessment and examine the convergence between the measures (Quittner et al., 2008).

Adherence in Childhood ADHD

Research regarding medication adherence in childhood ADHD is limited. What does exist is restricted by heterogeneous methodology (Chacko, Newcorn, Feirsen, & Uderman, 2010; Gajria et al., 2014). Gajria and colleagues (2014) conducted a systematic review of 91 original studies and 36 expert opinion reviews published on the topic between 1990 and 2013. Authors identified 25 studies reporting discontinuation or continuation/persistence rates focused on children and adolescents only. However, only four studies reported data similar enough to calculate pooled results. These studies generally defined persistence as number of days of continuous use of index (i.e., first or original) medication without a specified gap period of 30 days. Persistence results, reported as mean treatment duration, were 135.97 days for stimulant medications. Short-acting medications had the shortest treatment duration of 92.99 days. Authors identified 12 studies reporting adherence results, defined as number of days of medication supplied during pre-specified period, for patients 18 years of age or younger. Quantitative results of pooled adherence data indicated mean medication possession ratios (MPR; ratio of number of days with medication supply to total number of days in defined period) of 0.57 for stimulants in studies with 12-month follow-up and 0.49 in studies with 6-month follow-up.

Chacko and colleagues (2010) also conducted a literature review of 17 empirical studies on ADHD medication adherence in youth. These authors did not conduct any quantitative analyses, but reported a synthesis of the existing literature similar to Gajria and colleagues

(2014). Results suggested consistent use of stimulant medication is evident in 1/3 to 2/3 of prescribed youth. Studies also indicated that while short-term adherence varies considerably, long-term adherence is generally poor. These rates and medication use patterns are similar to those reported in childhood chronic medical conditions (Rapoff, 2010). A large number of families demonstrate almost immediate poor adherence to ADHD medications (Miller, Lalonde, McGrail, 2004). In fact, approximately 20% never fill more than one prescription (Miller et al., 2004).

Gajria et al., (2014) also reported results of 31 original studies examining reasons for treatment discontinuation among children and adolescents. The most frequently reported reasons were ineffectiveness/suboptimal response (21 studies), and adverse effects (21 studies). Poor adherence was reported as a reason in seven studies. Interestingly, the authors also reported results based on 24 expert opinion articles. According to expert opinion, the most frequently reported reasons for treatment discontinuation among children and adolescents were adverse effects (15 studies), dosing inconvenience (10 studies), patient attitude (8 studies), and social stigma (8 studies).

These reviews have highlighted the current state of the literature regarding medication adherence in childhood ADHD. Most literature has solely focused on stimulant medications. Marginal improvement in adherence has been reported with extended-release medications (Faraone, Biederman, & Zimmerman, 2007; Marcus, Wan, Kemner, & Olfson, 2005). Higher adherence rates have been reported in clinical research as opposed to community samples (Charach, Ickowicz, & Schachar, 2004; Jensen et al., 2007; Thiruchelvam, Charach, & Schachar, 2001).

Caregiver Beliefs and Attitudes about ADHD

Data discussed above indicate the relatively high rates of medication nonadherence in childhood ADHD. In addition to factors common to pediatric chronic illness conditions (Rapoff, 2010), researchers postulate factors that uniquely influence medication adherence in childhood ADHD (Chacko et al., 2010; Hoza, Johnston, Pillow, & Ascough, 2006). Many of these involve caregiver beliefs or attitudes about both assessment and treatment of ADHD. This approach is reasonable given that caregivers are the “gatekeepers,” or ultimate decision-makers, concerning pediatric treatment (Hoza et al., 2006). While much of this work is preliminary, relevant findings from qualitative and quantitative studies are discussed below.

Qualitative Studies. Ahmed, McCaffery, & Aslani (2013) conducted a systematic review of qualitative studies examining considerations reported by caregivers who are deciding whether to initiate or continue stimulant medication for their child. Authors searched five electronic databases for peer-reviewed, English-language studies published between January 1980 and September 2011 with relevant MeSH terms and keywords. Of 348 identified citations, 11 met the following eligibility criteria: (a) used qualitative methods; (b) involved a treatment decision, made by caregiver(s) of a child, about use of stimulant medication; (c) child was officially diagnosed with ADHD; and (d) examined factors involved in the caregiver treatment decision-making process.

The 11 studies, mostly conducted in the United States ($n = 6$), included a total of 335 participants. The authors identified four major themes across studies: (a) confronting the diagnosis; (b) external influences; (c) apprehension regarding stimulant therapy; and (d) experiences with the healthcare system.

Caregivers reported struggling to accept their child’s ADHD diagnosis, often exacerbated by trying to reconcile the image of children portrayed in the media with ADHD with the image

of their own child. In addition to media portrayals, caregivers reported relying on an acquaintance that was a caregiver of a child with ADHD for information. Many caregivers expressed hesitancy to accept ADHD as a legitimate condition. Similarly, caregivers often cited short diagnostic evaluations as evidence against a biological etiology. Several studies reported instances of one caregiver in agreement with ADHD diagnosis while the other was in complete opposition. Interestingly, caregivers frequently accounted for their child's behavior in other ways such as "boys will be boys" (Singh, 2003).

Caregivers identified several external sources of influence during the decision-making process. They often cited media coverage focusing on sensationalized versions of ADHD-related behaviors and treatment as troubling sources (Brinkman et al., 2009; Charach, Skyba, Cook, & Antle, 2006; dosReis, Barksdale, Sherman, Maloney, & Charach, 2010; dosReis, Zito, Safer, Soeken, Mitchell, & Ellwood, 2003; Jackson & Peters, 2008; Taylor, O'Donoghue, & Houghton, 2006). Caregivers discussed how media coverage of "overprescribing" of ADHD medications, addictive properties of medications, and portrayals of children treated with medication as "zombie-like," influenced their treatment decisions (Brinkman et al., 2009; dosReis et al., 2010). They also discussed the contribution of media coverage to blaming caregivers as unwilling to or incapable of parenting their child because they choose to medicate their child (Charach et al., 2006; Taylor et al., 2006). Caregivers reported that the views and opinions of others within their social networks and personnel from child's school similarly influence their treatment decisions (Brinkman et al., 2009; Bussing & Gary, 2001; Charach et al., 2006; Fiks, Hughes, Gafen, Guevara, Barg, 2011; Hansen & Hansen, 2006; Jackson & Peters, 2008; Leslie, Plemmons, Monn, & Palinkas, 2007).

In each of the 11 included studies, caregivers described concerns specific to stimulant medications. They expressed concern about immediate side effects (e.g., growth stunting, liver damage, personality changes, appetite suppression) and long-term effects. Caregivers also indicated fears of labeling and social isolation associated with child use of stimulant medications (Brinkman et al., 2009; Charach, et al., 2006; dosReis et al., 2010; Singh, 2003; Taylor et al., 2006). Some caregivers stated that financial burden of stimulant medications played a role in their treatment decisions (Fiks et al., 2011; Leslie et al., 2007).

All identified studies explored the influence of caregivers' experiences with the healthcare system on treatment decisions. Caregivers reported problematic interactions with healthcare providers characterized by perceived failure to effectively communicate and exchange information. Caregivers explained that these interactions left them feeling marginalized and doubting healthcare providers' recommendations, which exacerbated concerns of lax prescription practices (Brinkman et al., 2009; Bussing & Gary, 2001; Charach et al., 2006; dosReis et al., 2003; Leslie et al., 2007; Taylor et al., 2006).

Quantitative Studies. Given numerous caregiver misconceptions of ADHD (e.g., sugar and diet affect hyperactivity; dosReis et al., 2003), it seems intuitive that providing caregivers with accurate knowledge of ADHD would increase participation in evidence-based treatments for ADHD (Hoza et al., 2006). Studies have demonstrated that increased ADHD knowledge is positively correlated with acceptability of and willingness to pursue evidence-based treatments (Bennet, Power, Rostain, & Carr, 1996; Liu, Robin, Brenner, & Eastman, 1991). However, they have been limited by use of analog designs. Evidence demonstrating actual treatment use differences over time is limited (Bennett et al., 1996; Corkum, Rimer, & Schachar, 1999).

Given the preliminary nature of research specifically targeting childhood ADHD, it is helpful to consider findings from similar, but more established literature such as adherence to pediatric medical regimens. For example, educational adherence-promotion interventions (e.g., asthma, diabetes) have demonstrated a small effect size (Kahana, Drotar, & Frazier, 2008). Thus, educational strategies are typically combined with behavioral strategies, which have demonstrated a medium effect size (Graves, Roberts, Rapoff, & Boyer, 2010; Kahana, Drotar, & Frazier, 2008; Rapoff, 2010). These findings suggest that increased knowledge or educational strategies are critical, but not adequate for treatment engagement or adherence (Quittner et al., 2008; Rapoff, 2010).

Some researchers highlight parenting efficacy as a promising predictor of treatment initiation and adherence for ADHD; however, empirical support is limited (Hoza et al., 2006). Hoza and colleagues (2000) found, among other constructs, that low parenting efficacy in fathers was associated with poorer outcomes in a subsample of MTA participants. This association maintained after controlling for MTA treatment effects. Jiang and colleagues (2014) found a similar, but less robust association between parenting efficacy and ratings of treatment acceptability and effectiveness of behavioral parent training. This study is also limited by an analog design with conclusions more relevant to “intentions” than actual behavior (e.g., Maniadaki, Sonuga-Barke, & Kakouros, 2006). While self-efficacy is a useful and robust construct in predicting health-related behaviors, particularly in adults, evidence does not currently exist that it may be changed directly (Rapoff, 2010).

Caregiver Perception of Child Functional Impairment. As discussed earlier, functional impairment is a key component of EBA for ADHD. Functional impairment, not behavioral symptoms (e.g., inattention, hyperactivity), is most predictive of long-term outcome;

symptom remission does not necessarily coincide with recovery of function (Harrison, Vannest, & Reynolds, 2011; Hinshaw et al., 2006; Mick, Faraone, & Biederman, 2004). Children are typically referred for treatment based on functional problems in one or more domains commonly associated with impairment in children with ADHD: family functioning, peer relationships, and academic functioning (Angold, Costello, Farmer, Burns, & Erkanli, 1999; Evans & Youngstrom, 2006; Pelham, Fabiano, & Massetti, 2005). These domains may then be used to determine treatment goals (Fiks, Mayne, DeBartolo, Power, & Guevara, 2013; Pelham & Fabiano, 2001). Caregiver perception of child's functional impairment may also play a role in decision to initiate and continue treatment.

Jiang and colleagues (2014) examined functional impairment in ADHD as a predictor of treatment acceptability. Results indicated that greater impairment predicted (using higher linear modeling) higher acceptability of combined behavioral and pharmacological treatment. However, this result was not found for behavioral or pharmacological treatment in isolation. While this finding provides initial support of functional impairment as a predictor of treatment acceptability, it is limited by the analog and retrospective nature of study design.

Specifically, mothers who completed impairment measures were asked to "think of their child's functioning as it would be off medication" (Jiang et al., 2014, p. 536). This is particularly problematic because 75% of the children were currently taking ADHD medication, and 67% of those not taking medication at the time of the study, had taken it in the past. Likewise, these mothers may have had to think back several years when rating their child's behavior as children were diagnosed for an average of four years at the time of the study. Another limitation is that mothers were reporting treatment acceptability for a hypothetical child (i.e., not their own); thus, no conclusions may be drawn regarding the mothers' actual treatment decisions.

Variables in Current Study

The current study considered the state of the literature discussed above and the broader literature of adherence to childhood chronic illness in selection of predictor variables of adherence to ADHD medication outcomes. Various theories have been proposed to explain why individuals do or do not adhere to medical regimens. Among those most often cited are the Health Belief Model (HBM) (Becker, 1974; Janz & Becker, 1984), Social Cognitive Theory (SCT) (Bandura, 1986, 1992, 1994), and the Theory of Reasoned Action (TRA) (Ajzen & Fishbein, 1980; Fishbein, 1980; Fishbein & Ajzen, 1975). The current study sought to follow the recommendation that the best way to advance the field is to take an integrative approach and apply common principles across theories while maintaining unique conceptualizations of specific constructs (Rapoff, 2010).

Predictor variables for the current study were selected for theoretical and practical/pragmatic purposes. First, measuring caregiver perception of child functional impairment allows for application of the construct of “perceived severity” in the Health Belief Model (HBM; Rosenstock, 1974). The HBM is a widely studied theory of behavior change that has been extended to research on adherence to treatment regimens (Becker, 1974; Bush & Iannotti, 1990; Clark & Houle, 2009; Janz & Becker, 1984; Radius, Becker, Rosenstock, Drachman, Schubert, & Teets, 1978; Rapoff, 2010). Second, as discussed, functional impairment is an important component of EBA in ADHD. Thus, its inclusion is a cost-effective approach that may further our understanding of an already established construct. Third, functional impairment is particularly important given its relationship with long-term outcomes.

A variable examining caregiver response to physician recommendation of medication was also included for several other reasons. First, caregiver report of the physician’s medication recommendation as “hasty” allows for application of the construct of “perceived susceptibility”

in the HBM. This construct includes the caregiver belief in or acceptance of a diagnosis (Becker, 1974; Rapoff, 2010). Second, given the evolving nature of healthcare that increasingly values integration, we selected predictors of potential interest to healthcare providers in general (e.g., mental health professionals and physicians). Third, if the current study suggests these constructs have promise as predictors of adherence to ADHD medication, then researchers may consult already existing literatures in EBA of ADHD and effective physician-patient interactions (e.g., shared decision-making) when considering interventions to alter these attitudes/beliefs.

Purpose of Study

The purpose of the current study was to test a regression model predicting adherence to ADHD medication.

Study hypothesis.

Hypothesis 1. It was expected that recognition by caregivers of child functional impairment, as measured by the Vanderbilt Attention-Deficit/Hyperactivity Disorder Parent Rating Scale (VADPRS) mean performance score, and report by caregivers of the doctor's recommendation to initiate ADHD medication as "hasty," as indicated using a visual analog scale (VAS), would account for statistically significant variance in adherence (not initiation) to ADHD medication.

Chapter 2

Methods and Procedures

Participants

Inclusion/exclusion criteria. Participants recruited for this study were caregivers of children who met the following inclusion criteria: (a) six to 12 years of age; (b) had a diagnosis made by a physician or psychologist of ADHD-C, ADHD-HI, ADHD-I, or ADHD NOS using DSM-IV diagnostic criteria (APA, 2000); and (c) were prescribed an FDA-approved medication to treat ADHD within six months from the time of recruitment (see Table 2 for list of eligible medications).

Table 2. *FDA-Approved Medications to Treat Attention-Deficit/Hyperactivity Disorder (ADHD) in Children*

Generic Name	Trade Name	Approved Age
amphetamine	Adderall	3 and older
amphetamine (extended release)	Adderall XR	6 and older
atomoxetine ^a	Strattera	6 and older
dexmethylphenidate	Focalin	6 and older
dexmethylphenidate (extended release)	Focalin XR	6 and older
dextroamphetamine	Dexedrine, Dextrostat	3 and older
guanfacine ^b	Intuniv	6 and older
lisdexamfetamine dimesylate	Vyvanse	6 and older
methamphetamine	Desoxyn	6 and older
methylphenidate	Ritalin	6 and older
methylphenidate (extended release)	Metadate CD, Metadate ER, Ritalin SR	6 and older
methylphenidate (long-acting)	Ritalin LA, Concerta	6 and older
methylphenidate patch	Daytrana	6 and older
methylphenidate (oral solution and chewable tablets)	Methylin	6 and older

Note. ^aAtomoxetine is in a class of medications called selective norepinephrine reuptake inhibitors. ^bGuanfacine is in a class of medications called centrally acting alpha_{2A}-adrenergic receptor agonists.

Caregivers were excluded from study participation if: (a) they did not speak English; (b) the child had a diagnosis by a physician or psychologist of PDD or Mental Retardation (MR) using DSM-IV diagnostic criteria (APA, 2000); (c) the child had a diagnosis of a chronic medical illness made by a physician that requires daily medication (e.g., asthma); or (d) the current ADHD medication trial was not the child's first (i.e., they had a history of ADHD medication prescriptions). Caregiver participants have been identified as participants and the target children (i.e., child who met above eligibility criteria) as children in the remainder of this document.

Location of study. Participant recruitment occurred at several locations: four primary care outpatient clinics in two academic medical centers, one private primary care outpatient clinic, one mental health clinic, multiple Children and Adults with ADD (CHADD) events, and via social media. Physicians in the primary care clinics have provided general pediatric care, well-child visits, physicals for sports and other activities, as well as treatment of acute illnesses. Two of these clinics have functioned within the Department of Pediatrics of the University of Kansas Medical Center (KUMC): Main Clinic on the third floor of the Medical Office Building in Kansas City, Kansas, and the University of Kansas (KU) Pediatrics Clinic in Prairie Village, Kansas. The remainder has functioned within the Department of General and Community Pediatrics of the University of Oklahoma Health Sciences Center (OUHSC) in Oklahoma City, Oklahoma. The private primary care outpatient clinic has served families in the Lawrence Kansas area for several decades. The mental health clinic has also functioned within the Department of Pediatrics of KUMC at the KU Pediatrics Clinic in Prairie Village, Kansas. Licensed psychologists who treat the problems of childhood and adolescence using an interdisciplinary approach have provided diagnosis and treatment in this clinic.

Participants also referred themselves to participate in the study by responding to information posted, with permission, on various social media sites (i.e., Facebook pages). Recruitment also occurred via the Pioneers Research Participant Registry (RPR) established by Frontiers: The Heartland Institute for Clinical and Translational Research, a collaborative initiative sponsored by KUMC and other hospitals and universities in the Kansas City, Kansas, region (see Appendix A for permission form).

Informed consent. Prior to participation in the study, caregiver consent was obtained in writing. Participants obtained the Informed Consent and Authorization to Release Information forms approved by the KUMC Human Subjects Committee (HSC) or the OUHSC Institutional Review Board (IRB), as appropriate. Research personnel reviewed these documents with participants in person or via telephone. Research personnel invited caregivers to ask questions and/or decline participation. They emphasized that participation was completely voluntary, may be withdrawn at any time without penalty, and did not affect the child's current or future care provided via KUMC or OUHSC.

Procedures

Recruitment. The lead Patient Service Representative (PSR) for the two KUMC General Pediatrics Clinics sent the Research Coordinator (RC), via secure email, a copy of the schedule of clinic appointments for the upcoming week. The RC screened all appointments with relevant appointment reasons (e.g., F/U Behavior) for eligibility criteria using the electronic medical record (EMR). When available, research personnel attended the appointment for potentially eligible patients. Nursing staff introduced the study to families using an HSC- or IRB-approved recruitment flyer (See Appendix B) during the child's appointment and research personnel gave interested families an initial study packet. Researchers completed informed

consent in person as time allowed without disrupting clinic flow. Otherwise, the RC completed the informed consent over the telephone in accordance with HSC or IRB protocol. Families who declined participation were not contacted again.

A similar procedure was utilized in the KUMC Behavioral Pediatrics clinic. The RC identified potentially eligible families and shared this information with each provider via secure email. Providers then approached the family in clinic to obtain permission for research personnel to contact family regarding study participation. RC then contacted interested families by telephone and mailed them an initial study packet.

For the OUHSC primary care clinic, the RC screened each provider's appointments for potentially eligible patients using the EMR. Given that research personnel were also clinic staff, they were generally able to attend clinic appointments and speak with the family in person. Again, researchers completed informed consent in person as time allowed without disrupting clinic flow. Otherwise, the RC completed the informed consent over the telephone in accordance with IRB protocol.

HSC-approved recruitment information was posted, with permission, to various relevant social media websites (e.g., local CHADD chapters). Families interested in participating contacted RC by telephone and/or email. Recruitment then occurred using the procedures already outlined. Research personnel also attended events where the audience was caregivers of children or adolescents with ADHD (e.g., CHADD support groups, Executive Function Junction Conference). The Practice Administrator for a private pediatric office in Lawrence, Kansas, sent potentially eligible patients an HSC-approved recruitment letter (see Appendix C). Interested families then contacted RC either by email, telephone, or postal mail. In these instances, we

contacted the child's healthcare provider, via fax and/or phone, to confirm ADHD diagnosis and currently prescribed medications (see Appendix D).

Recruitment also occurred using resources available via KUMC Bioinformatics. RC used the Healthcare Enterprise Repository for Ontological Narration (HERON) to complete a query identifying potentially eligible patients from the KUMC EMR. RC received approval from the Data Request Committee (DRC) and obtained information to contact those families identified by i2b2 data and registered for the Frontiers Research Participant Registry (Frontiers), a comprehensive registry of patients who granted permission to be contacted regarding participation in research studies. RC approached Frontiers patients by telephone using an HSC-approved script (see Appendix E).

Baseline. Participants either completed baseline measures in clinic or at home where they were later returned in a preaddressed postage-paid envelope. Participants completed a measure of ADHD symptom severity either during the recruitment appointment or one was obtained from the EMR. In some instances the child had already started taking medication, so this measure reflected child's behavior on medication.

RC faxed a copy of the Authorization to release protected health information signed by the child's legal representative along with a letter describing the study (see Appendix F) to the caregiver-identified pharmacy where the family obtains the child's medication. RC faxed these prescription history requests either directly to the specific pharmacy location or to the privacy office of the larger corporation.

Follow-up. Participants who initiated ADHD medication completed the Stimulant Adherence Measure (SAM) via telephone approximately one month after study enrollment. After completing the SAM interview, participants counted the number of pills remaining in the

child's medication bottle. Participants completed a second pill count via telephone approximately one week after the first. We calculated a pill count outcome using the following: (a) subtracted number of pill counted at Time 2 from the number counted at Time 1; (b) divided this product by the total number of pills prescribed over the one-week count interval; and (c) multiplied by 100 to obtain a percent of prescribed doses taken (Rapoff, 2010).

Participants completed follow-up measures using a secure web-based survey (i.e., Qualtrics). Those participants who did not have Internet access, or expressed a preference not to complete web-based measures, completed paper-pencil versions of follow-up measures and returned them by mail. RC faxed a second prescription history request to obtain additional pharmacy data.

Measures

All non-copyrighted measures for the current study were included in Appendices G through I.

Demographic Questionnaire & Protected Health Information (PHI) Sheet.

Questionnaires created for the current study collected basic demographic information such as age, sex, race/ethnicity, and marital status of primary caregiver. The questionnaires requested various measures of social class including caregivers' educational level, total family income, and school level indicators of poverty (i.e., enrollment in Title I schools) (Diemer, Mistry, Wadsworth, López, & Reimers, 2012). We also collected background variables previously found to be associated with willingness to initiate ADHD medication. Specifically, parents reported whether they had other children who have taken ADHD medication (Rostain, Power, & Atkins, 1993), and/or an acquaintance that has a child with ADHD (Bennett et al., 1999). We obtained relevant medical information such as specific ADHD diagnosis, date of diagnosis,

comorbid mental health diagnoses, and other treatments for ADHD. PHI was stored separately from other study data.

Medication Recommendation. A single-item questionnaire created for the current study measured the extent to which the caregiver perceives the child's doctor's recommendation to initiate ADHD medication as "hasty." Caregiver response was recorded using a VAS with 0 centimeters = *Completely Agree* and 7 centimeters = *Completely Disagree*. Qualitative studies have consistently reported parental concern and/or negative perception that ADHD medication is indiscriminately recommended to children without gathering enough information about the individual child (e.g., Brinkman et al., 2009; Charach et al., 2006; Coletti et al., 2012). To this writer's knowledge, a validated measure of this construct did not previously exist.

We considered a VAS an appropriate method of measuring this construct for several reasons. First, they have been established as a useful method of measuring subjective constructs (e.g., pain, mood, opinion) (Miller & Ferris, 1993; Wewers & Lowe, 1990). Second, they have commonly been regarded as a continuous scale with an approximately normal distribution (Miller & Ferris, 1993). Third, ultimate use of a VAS in a clinic setting has been feasible relative to more complex measures (Miller & Ferris, 1993; Wewers & Lowe, 1990).

Pharmacy Data. We obtained prescription refill data from the pharmacy (or pharmacies) identified by the family as their primary location(s) for obtaining medications. The study utilized a continuous measure of refill adherence focusing on the availability of medication calculated using pharmacy data (Steiner & Prochazka, 1997). We calculated a medication possession ratio (MPR) for each participant who accepted a prescription for an ADHD medication (Cramer et al., 2008; Marcus & Durkin, 2011). We calculated MPRs using the following: (a) summed the number of days' supply of medication obtained by refills (according

to pharmacy data); and (b) divided the total days from initially filling the ADHD medication until the end of study participation. The MPR was coded as zero for participants who accepted (i.e., took prescription from physician), but did not fill the prescription. The MPR was truncated at 1.00 for participants who had a surplus of medication, which likely resulted from dosage titration. We adjusted the MPRs for those participants who indicated they intended to skip medications on particular days (e.g., summer vacation, weekends). Thus, the study accounted for planned drug holidays.

SAMBA. The SAMBA scales measures child (ages five to 18 years) and parent attitudes toward ADHD medications (Harpur, Thompson, Daley, Abikoff, & Sonuga-Barke, 2008). Authors derived scales from principle components analysis with each factor having an eigenvalue > 1.0. The child version has 16 items comprising four scales: (a) perceived costs of medication; (b) perceived benefits of medication; (c) child stigma; and (d) resistance. All scales have been found to have acceptable internal consistency reliability ($\alpha > 0.70$). The parent version has 27 items comprising seven subscales: (a) perceived costs of medication; (b) perceived benefits of medication; (c) child stigma; (d) parent stigma; (e) child resistance; (f) dosing flexibility; and (g) parent medication-related inconsistency. All scales but one, parent medication-related inconsistency ($\alpha = 0.67$), have been shown to have acceptable internal consistency reliability ($\alpha > 0.70$). Respondents are asked to consider how true each questionnaire item is to their experience over the last three months of treatment. Both versions use a five-point Likert scale anchored with 1 = *Strongly Disagree* and 5 = *Strongly Agree*.

Positive and significant correlations between parent and child report have been reported: costs ($r = .70$), benefits ($r = .41$), child stigma ($r = .70$), and resistance ($r = .57$). Nevertheless, children reported significantly more costs and fewer benefits of ADHD medication than parents

(Benefits $t(108) = 5.60$; $p < 0.001$; Costs $t(105) = 3.31$; $p < 0.001$). The current study used only the parent version for multiple reasons. First, while child self-report is important, the current study was primarily interested in caregiver beliefs/attitudes as the ultimate decision-makers for this age group (Charach, Yeung, Volpe, Goodale, & dosReis, 2014; Hoza et al., 2006). Second, we decided that the reading and cognitive level of the child report was beyond the common abilities of children of this age.

SAM. The SAM is a semi-structured telephone interview designed to measure adherence to ADHD medication in children (Charach, Gajaria, Skyba, & Chen, 2008). The SAM is intended to be conversational and uses nonjudgmental language to elicit information regarding ADHD medication usage. Interviews with a parent and child are conducted separately and require approximately five to 15 minutes to complete. Parent respondents are asked to estimate how many pills their child missed over the past seven and 28 days. Child respondents are asked to report how many pills they missed over the past seven days only. We included only the parent version in the current study.

Charach and colleagues (2008) compared parent and child (ages eight to 15 years) report ($n = 22$) families using the Medication Event Monitoring System (MEMS) and the SAM each month for three months. Results indicated good to excellent agreement between the MEMS and SAM parent report (ICCs = 0.663 to 0.907) and good agreement between the MEMS and SAM child report (ICCs = 0.542 to 0.773). Inter-rater reliability between ratings made by the original interviewer and a second rater who coded based on audiotape was excellent (ICCs = 0.927 to 0.956). The SAM appears to be a stable measure as no significant differences were found between interviews at months one, two, or three.

VADPRS. The VADPRS is an ADHD symptom rating scale based on DSM-IV criteria. The VADPRS includes 47 items assessing symptoms of ADHD-I, ADHD-HI, ODD, CD, as well as anxiety and depression. The last eight items evaluate impairment in academic performance and interpersonal relationships. Parents are instructed to consider what is age appropriate when completing ratings. They use a four-point Likert scale anchored with 0 = *Never* and 3 = *Very Often* to rate how often their child exhibited various behaviors in the past six months. Items rated a 2 or 3 are considered positive responses. The performance items are rated using a five-point Likert scale anchored with 1 = *Excellent* and 5 = *Problematic*. Items rated a 4 or 5 are positive responses indicative of impairment. The VADPRS is scored by adding the number of positive responses in each domain and calculating a mean performance score.

The VADPRS is included as part of the AAP and NICHQ ADHD Toolkit (AAP & NICHQ, 2002), and is established as a measure for EBA of ADHD (AACAP Work Group on Quality Issues, 2007; Pelham et al., 2005). The VADPRS has demonstrated good internal consistency ($\alpha = 0.94$ to 0.95), and fit with a four-factor model using confirmatory factor analysis (ADHD-I, ADHD-HI, Externalizing Problems, Internalizing Problems)(Wolraich et al., 2003). The VADPRS is easy to read at slightly below third grade level (Wolraich et al., 2003). A version of the scale to be completed by a teacher is also available (Wolraich, Feurer, Hannah, Baumgaertel, & Pinnock, 1998).

The study calculated descriptive statistics for each of the following VADPRS summary scores: (a) number of positive responses to ADHD-I items; (b) number of positive responses to ADHD-HI items; (c) total symptom score for ADHD items; (d) number of positive responses to ODD items; (e) number of positive responses to CD items; (f) number of positive responses to anxiety and depression items; (g) number of positive responses to performance items; and (h)

mean performance score. These data indicated the severity of ADHD in the sample. The mean performance score for those measures reflecting child's behavior off medication was included in regression analyses as a measure of functional impairment.

Statistical analyses

Missing data. Given the small sample size, we did not have enough information to use any methods to account for missing data (e.g., multiple imputation).

Analysis of results. We completed all analyses using the Statistical Package for Social Sciences (SPSS, Armonk, NY) version 21. The RC entered data. Prior to conducting analyses, we double-checked that all data were entered correctly. We did not check for assumptions of normality as the small sample size did not allow for this. Thus, we used non-parametric alternatives that do not rely on an assumption of normality. Given the preliminary nature of the current study, alpha level was set at $\alpha = .10$.

Preliminary analyses. We utilized the One-Sample Wilcoxon Signed Rank Test to compare adherence rates in the current sample against those that have been reported in the literature. We used the reported mean as our null hypothesized median, as there was no alternative because studies did not provide median levels. We used the Independent-Samples Mann-Whitney *U* Test to assess for significant differences in a continuous outcome between two independent groups within the current sample. We assessed demographic and condition-specific variables for relation to primary dependent measure (i.e., MPR) using Kendall's tau as the correlation measure because it does not require data to be normally distributed or the relationship between variables to be linear.

Hypothesis 1. We performed a standard multiple regression using the forced entry method between MPR as the dependent variable and the following as independent variables

(IVs): demographic and/or condition-specific variables that significantly correlated with MPR, recognition by caregivers of child functional impairment, and report by caregivers of the doctor's recommendation to initiate ADHD medication as "hasty." Only those VADPRS measures completed when child was not on medication were included in this analysis. In order to prevent issues of multicollinearity, we assessed for significant correlations between IVs prior to including them in regression analyses. We included bootstrapping using the bias corrected and accelerated method for calculating 95% confidence intervals, which were used to test the null hypothesis of no relationship (slope = 0) at the $\alpha = .05$ significance level.

Chapter 3

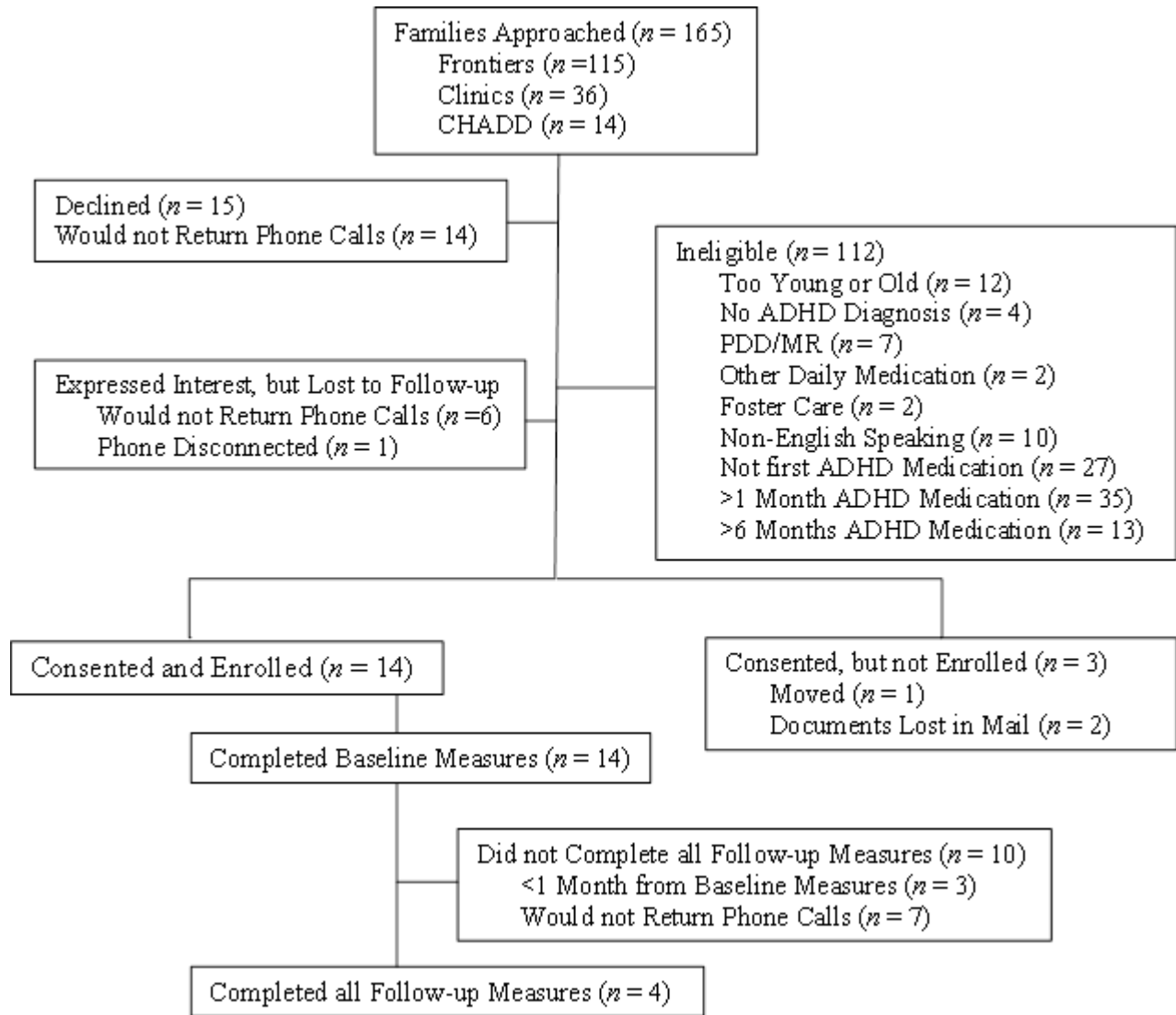
Results

Participants

Recruitment. We actively recruited participants from July 2, 2013 to November 3, 2014. Of 165 families approached, 112 did not meet eligibility criteria (see Figure 1). The majority (i.e., 67%) of these families did not meet eligibility criteria due to ADHD medication history: 27 children had taken a different ADHD medication in the past; 35 children did not meet the original time criterion of having been prescribed ADHD medication within one month of recruitment; and 13 did not meet the revised time criterion of having been prescribed ADHD medication within six months of recruitment. Fifteen of the families approached declined participation. The remainder ($n = 21$) could not be contacted to complete informed consent. Participants were recruited from the following sources: 10 from OUHSC; four from KUMC Behavioral Pediatrics clinics; two from CHADD events; and one from KUMC Primary Care clinics.

Participant characteristics. Of the 14 participants, the majority was female (92.86%), had an annual household income lower than \$50,000 (64.7%), and had obtained greater than a high school education (70.6%). Half of the participants were married. Participants' age at study entry ranged from 27.39 to 63.22 years ($M = 37.78$, $SD = 9.04$). Age at study entry for participants' partner (i.e., most often child's father) ranged from 30.55 to 51.44 years ($M = 37.70$, $SD = 6.96$). Six participants (35.3%) had children, other than the target child, who had taken ADHD medication. Eight participants (47.1%) had a family member, friend, or acquaintance that had a child who has taken ADHD medication.

Figure 1. Participant enrollment.



The majority of the children were male (70.6%), currently attending school below third grade (52.9%), at a low-income, Title 1 school (52.9%). Of those attending a Title 1 school, the percent of children at the school considered low-income ranged from 49.20 to 98.40 ($M = 80.96$, $SD = 17.07$). Five children (29.4%) were non-Hispanic White. Age at study entry for target child ranged from 6.16 to 12.09 years ($M = 8.80$, $SD = 2.04$). A psychologist, as opposed to physician, diagnosed a majority of the children with ADHD (47.1%). The majority of children

were prescribed a CNS once per day (47.1%). Age at time of ADHD diagnosis for child ranged from 5.83 to 11.72 years ($M = 7.81$, $SD = 1.70$), and age at start of ADHD treatment ranged from 5.90 to 11.72 years ($M = 7.92$, $SD = 1.72$). The majority of children had used evidence-based treatment (64.7%), not including FDA-approved medication, to treat ADHD. The majority of children had also used non-evidence-based treatment (64.3%). See Tables 3 and 4.

Table 3. *Categorical Demographic Variables (N = 14)*

Variable	<i>n</i> (%)
Caregiver Sex	
Male	13 (93%)
Female	1 (7%)
Marital Status	
Single	3 (21%)
Married	7 (50%)
Divorced	1 (7%)
Not Married, Live with Partner	3 (21%)
Household Income	
\$0-\$10,000	2 (14%)
\$10,001-\$30,000	1 (7%)
\$30,001-\$50,000	8 (57%)
\$50,001-\$70,000	2 (14%)
\$70,001-\$100,000	0 (0%)
Above \$100,001	1 (7%)
Education	
High School Graduate	2 (14%)
Some College or Specialized Training	8 (57%)
College Graduate	4 (29%)
Child Sex	
Male	12 (86%)
Female	2 (14%)
Child Race	
Black or African American	4 (29%)
White	1 (7%)
Multiracial	9 (64%)
Child Ethnicity	
Not Hispanic or Latino	8 (56%)
Hispanic or Latino	6 (43%)

Table 4. *Continuous Demographic Variables (N = 14)*

Variable	<i>M</i>	<i>SD</i>
Mother Age	37.78	9.04
Father Age ^a	37.70	6.96
Child Age	8.80	2.04
Child Age at Diagnosis ^a	7.81	1.70
Child Age at Start of Treatment ^a	7.92	1.72

Note. ^a*n* = 13.

ADHD symptoms and impairment. Nine participants completed the VADPRS when the child was not on ADHD medication. As expected, results from these reports differed significantly from those of participants whose child was already on medication (See Table 5). For the stimulant naïve children, the number of positive responses (i.e., rated “Often” or “Very Often”) to ADHD-I and ADHD-HI items, respectively, ranged from six to nine ($M = 8.38$, $Mdn = 9.00$, $SD = 1.06$) and one to nine ($M = 6.33$, $Mdn = 7.00$, $SD = 3.12$). The Total ADHD Symptom Score ranged from 28 to 50 ($M = 41.00$, $Mdn = 44.00$, $SD = 8.57$). Of note, the number of positive responses to ODD items ranged from zero to eight ($M = 4.00$, $Mdn = 4.00$, $SD = 2.98$) with a mean indicative of a positive screening (i.e., requires four of eight items to be positive; AAP & NICHQ, 2002). One participant reported on the Demographic Questionnaire that the child had a comorbid diagnosis of ODD. One participant also reported that the child had a comorbid diagnosis of Generalized Anxiety Disorder. However, overall results did not indicate a positive screening for anxiety and depression ($M = 1.38$, $Mdn = 1.50$, $SD = 1.41$). When considering functional impairment, the number of positive responses (i.e., rated “Somewhat of a Problem” or “Problematic”) to Performance items ranged from one to five ($M = 3.67$, $Mdn = 4.00$, $SD = 1.66$). The Mean Performance scale ranged from two to four ($M = 3.40$, $Mdn = 3.63$,

$SD = .64$). These results are comparable to those reported elsewhere for children with ADHD and higher than for children with no diagnosis (Becker, Langberg, Vaughn, & Epstein, 2012).

Table 5. *Vanderbilt ADHD Diagnostic Parent Rating Scales*

Variable	Off Medication ^a			On Medication			p^b
	M	Mdn	SD	M	Mdn	SD	
Positive Responses to ADHD-I Items ^c	8.38	9.00	1.06	5.00	7.00	3.24	.019*
n	8			5			
Positive Responses to ADHD-HI Items	6.33	7.00	3.12	4.20	2.00	3.03	.364
n	9			5			
Total Symptom Score for ADHD Items	41.00	44.00	8.57	27.00	31.00	8.60	.045*
n	8			5			
Positive Responses to ODD Items	4.00	4.00	2.98	.60	0.00	.89	.030*
n	8			5			
Positive Responses to CD Items	1.25	1.00	1.49	.20	0.00	.45	.171
n	8			5			
Positive Responses to Anx. & Dep. Items	1.38	1.50	1.41	1.60	1.00	1.82	1.00
n	8			5			
Positive Responses to Performance Items ^d	3.67	4.00	1.66	1.60	2.00	1.14	.042*
n	9			5			
Mean Performance Score	3.40	3.63	.64	2.93	2.88	.40	.147
n	9			5			

Note. ADHD-HI = ADHD-Hyperactive/Impulsive. ADHD-I = ADHD-Inattention. Anx. = Anxiety. CD = Conduct Disorder. Dep. = Depression. ODD = Oppositional Defiant Disorder. ^aChild was on or off medication when measure was completed. ^bIndependent-Samples Mann-Whitney U Test. ^cPositive responses to symptom items are those rated “Often” or “Very Often.” ^dPositive responses to performance items are those rated “Somewhat of a Problem” or “Problematic.”

Three participants completed the VADPRS follow-up measure of child's behavior while on medication. These results were lower than the initial report. The number of positive responses to ADHD-I and ADHD-HI items, respectively, ranged from zero to five ($M = 1.67$, $Mdn = .00$, $SD = 2.89$) and zero to nine ($M = 3.33$, $Mdn = 1.00$, $SD = 4.93$). The Total ADHD Symptom Score ranged from 15 to 50 ($M = 24.67$, $Mdn = 19.00$, $SD = 15.31$). The number of positive response to Performance items ranged from zero to one ($M = .67$, $Mdn = 1.00$, $SD = .58$). The Mean Performance scale ranged from 2.13 to 3.13 ($M = 2.67$, $Mdn = 2.75$, $SD = .51$).

Preliminary Analyses

Adherence. We obtained pharmacy data, which allowed us to calculate MPRs, for 14 participants. The number of days included in the MPR ranged from 22 to 307 ($M = 164.45$, $SD = 100.01$). MPR ranged from 0.00 to 1.00 ($M = .65$, $SD = .38$). The median ($Mdn = .75$) was not significantly different from what has been reported in the ADHD medication adherence literature ($Mdn = .49$), $T = 1.795$, $p = .07$ (Gajria et al., 2014). The MPR for three participants was coded as 0.00 because they accepted, but did not fill a prescription for ADHD. When excluding these participants, MPR ranged from .56 to 1.00 ($M = .83$, $SD = .17$). The median ($Mdn = .80$) was significantly higher from what has been previously reported ($Mdn = .49$), $T = 2.675$, $p = .007$ (Gajria et al., 2014).

Five participants completed the SAM. Participant recall for number of doses missed during the past seven days ranged from zero to four ($M = .80$, $Mdn = .00$, $SD = 1.79$). Number of doses missed during the past 28 days ranged from zero to 16 ($M = 3.80$, $Mdn = .00$, $SD = 6.94$). However, participants accounted for missed doses by describing them as planned drug holidays. Accounting for these resulted in 100.00% adherent for all participants over the past week and 95.00 to 100.00% ($M = 99.00$, $Mdn = 100.00$, $SD = 2.24$) over the past 28 days. Four of these five participants also completed a pill count outcome. One participant explained that she did not

have access to the child’s medication as it was kept at school. Percent adherent according to pill count ranged from zero to 93.33 ($M = 57.96$, $Mdn = 69.26$, $SD = 42.71$). Adherence outcomes for each participant are included in Table 6.

Table 6. *Percent Adherence for Participants with Multiple Measures*

SAM – 7	SAM – 28	Pill Count	MPR (Days ^a)
100.00	100.00	51.85	55.56 (162)
100.00	100.00	-	100.00 (28)
100.00	100.00	93.33	100.00 (41)
100.00	95.00	0.00	68.00 (307)
100.00	100.00	86.67	100.00 (203)

Note. SAM – 7 = Stimulant Adherence Measure – Doses missed past seven days. SAM – 28 = Stimulant Adherence Measure – Doses missed past 28 days. MPR = Medication possession ratio. ^aNumber of days included in MPR.

Medication Recommendation. Fourteen participants completed the VAS measuring the extent to which they perceived the child’s doctor’s recommendation to initiate ADHD medication at “hasty.” Responses ranged from zero (i.e., “Completely Agree”) to seven (i.e., “Completely Disagree;” $M = 5.24$, $SD = 2.36$). The median was 6.80 with a mode of 7.0. The distribution of this measure differed significantly between participants who did ($M = 6.11$, $Mdn = 7.00$, $SD = 1.63$) and did not ($M = 2.07$, $Mdn = 2.50$, $SD = 1.89$) fill a prescription of ADHD medication for the child, $T = 2.350$, $p = .022$.

SAM. Five participants completed the SAM. Participants generally reported that the child was doing well with ADHD medication. One participant discussed her decision to allow her child drug holidays over the weekend. Two participants reported that the child was not experiencing any medication side effects. Of the three participants who reported side effects, three reported experiencing loss of appetite, two reported experiencing sleep difficulties, one reported experiencing headaches, and one reported experiencing tics. One participant identified the child’s emotional lability as an additional side effect. Two participants stated that they

considered stopping the medication. The child of both of these participants had been taking ADHD medication longer than the mean for the current sample. Two participants who stated they had not considered stopping the medication cited the child's improvement as a reason. All participants reported forgetting to give child ADHD medication less than once per month. See Table 7 for details.

SAMBA. Five participants completed the SAMBA. Results were similar to those reported by the scale developers (Harpur et al., 2008). The subscale with the highest mean was Benefits ($M = 14.80, SD = 3.11$). The subscale with the lowest mean was Child Stigma ($M = 5.60, SD = 1.67$). The mean for other subscales ranged from 7.60 (Resistance) and 9.80 (Parental Stigma). See Table 8 for details.

Table 8. *Southampton ADHD Medication Behaviour and Attitudes Scale*

Subscale	Min	Max	<i>M</i>	<i>Mdn</i>	<i>SD</i>
Benefits	11	18	14.80	14.00	3.11
Costs	4	15	8.40	8.00	4.16
Resistance	6	8	7.60	8.00	.89
Child Stigma	4	8	5.60	6.00	1.67
Parental Stigma	4	15	9.80	12.00	5.40
Flexibility	4	15	8.80	10.00	4.44
Inconsistent	3	8	4.60	4.00	2.07

Note. $N = 5$.

Table 7. *Excerpts from Stimulant Adherence Measure*

Interview question	Participant Response
How is (child's name) doing with the ADHD medication?	<p>"He is actually doing pretty good. He's still a bit hyperactive. They changed the medication, so he's taking more."</p> <p>"He is doing very well."</p> <p>"Doing OK. He's definitely got more focus, but it either wears off really quickly. He can sit and do his schoolwork for about 30 minutes, but he's like a bunny everywhere."</p> <p>"So so. We actually go see his doctor next Thursday to discuss it because it's wearing off by 4 or 5pm. Going to bed is becoming an issue. We get up at 5:30 every morning."</p> <p>"The medication is good. He does really well when it's on, but things get hard when it wears off in the afternoon."</p>
What made you decide to not give (child's name) their medication on weekends?	<p>"Him being on medication was a big thing for me. I just don't want my kids on medication. But weekends I just let him be a kid. Because I know medications restrict him from things he wants to do. He's got energy to burn."</p>
Is (child's name) experiencing loss of appetite? If yes, do you think this is related to the medication?	<p>"Yes. Severe loss of appetite. He was basically like a garbage disposal before meds."</p> <p>"Yes and no. We usually try to feed him before he takes his pill in the morning. He doesn't usually eat lunch. He's hungry by dinner, but starving at bedtime."</p> <p>"Yes. It seems to suppress his appetite for awhile, but once it wears off he is the same."</p>
Is (child's name) experiencing headaches? If yes, do you think this is related to the medication?	<p>"Yes, when he first started."</p>

Table 7 Continued. *Excerpts from Stimulant Adherence Measure*

Interview question	Participant Response
Is (child's name) experiencing trouble getting to sleep or staying asleep? If yes, do you think this is related to the medication?	<p>"Yes, but he's always had trouble with sleep."</p> <p>"Yes, he's had trouble here and there. He is a sleepwalker. He occasionally gets up and comes to our room. And he couldn't make his mind slow or stop."</p>
Is (child's name) experiencing tics? If yes, do you think this is related to the medication?	<p>"Yes, he has to have something in his mouth at all times. He will chew on his shirt if he doesn't have anything else. He chews bubblegum in class to prevent this."</p>
Is child experiencing any other side effects?	<p>"Yes, he's very emotional. Like a rollercoaster. He might get in trouble for the slightest thing and have a meltdown."</p>
Have you ever thought about stopping the medication? Why or why not?	<p>"No because he's doing better now."</p> <p>"No, because it's helping him. He's doing better in school now than without."</p> <p>"No. We just started it. We've thought about different medications because this one doesn't work with hyperactivity."</p> <p>"Yes, because we try to weigh the good with the bad. From the emotional stuff and having to comfort him or it's bouncing off the walls. Has no concentration or self-control."</p> <p>"Yes. Sometimes when he's on the med he seems depressed. I don't see any feelings or excitement."</p>
How often do you think you forget to give your child their medication, for example because it's a busy time of year or a hectic morning?	<p>"I do forget sometimes, but he remembers."</p> <p>"Before I started keeping it at the school, would be once per month. But now, not at all."</p> <p>"Maybe once per month."</p> <p>"Never ever."</p> <p>"Several times in the beginning, but in the last two months we haven't missed any."</p>

Correlations. There was a significant negative correlation using Kendall's tau between the number of days included in the MPR and the primary adherence outcome (i.e., MPR), $\tau = -.41, p$ (one-tailed) = .05. There were significant relationships between demographic variables and MPR. Specifically, percent of children at Title 1 school considered low-income, $\tau = -.50, p$ (two-tailed) = .07, and highest grade-level completed by participant being greater than high school, $\tau = -.41, p$ (two-tailed) = .10 were negatively correlated with MPR. VADPRS mean Performance score was not significantly associated with MPR, $\tau = .03, p$ (one-tailed) = .39, nor was number of positive responses to Performance items, $\tau = .17, p$ (one-tailed) > .34. Report by participants of the doctor's recommendation to initiate ADHD medication as "hasty" was not significantly associated with MPR, $\tau = .19, p$ (one-tailed) > .19. The following variables were also not significantly correlated with MPR: marital status of participant; participant has another child with ADHD medication; participant has a family member, friend, or acquaintance that has a child who has taken ADHD medication; household income; child health insurance; child gender; child grade level; child Race/Ethnicity; education of child's father; child's age; participant's age; age of child's father; use of evidence-based or non-evidence-based treatment; child age at ADHD diagnosis; child age at start of ADHD treatment; and remaining VADPRS scales.

Study Hypothesis

Hypothesis 1. Given the negligible correlations between hypothesized predictors (i.e., mean Performance score, medication VAS), they were not included in regression analyses. Standard multiple regression was performed with variables that significantly correlated with MPR (i.e., number of days included in MPR, participant education, and percent of children at Title 1 school considered low-income) as predictors. No adjustments for multicollinearity were

necessary as none of these IVs significantly correlated with each other. A solution with three IVs was not significant, $F = 3.260$, $p = .14$, $\Delta R^2 = .492$. A solution using number of days included in MPR as the only predictor was significant, $F = 3.471$, $p = .10$, $\Delta R^2 = .198$.

Chapter 4

Discussion

The hypothesis that recognition by caregivers of child functional impairment and report by caregivers of the doctor's recommendation to initiate ADHD medication as "hasty" would account for statistically significant variance in adherence to ADHD medication was not supported. None of these predictor variables were significantly associated with the outcome variable (i.e., MPR). Unfortunately, the conclusions that may be drawn from this finding are limited as this study was underpowered (Cohen, 1992). Nevertheless, the correlations were in the hypothesized directions. Most notably, as participants disagreed with the statement, "My child's doctor was too hasty in his/her recommendation of ADHD medication," their adherence outcome increased. This finding provides preliminary data to suggest that caregivers' perception of their child's doctor as "hasty" in their recommendation of ADHD medication is related to actual adherence behavior. To this writer's knowledge, this is the first study to report this relationship using objective adherence data and not only caregiver report (Ahmed et al., 2013).

Thus, clinicians who wish to improve adherence to ADHD medication in children may do so by working toward improving interactions between physician and caregivers. Improving the quality or effectiveness of these interactions may be influenced by increasing shared decision-making between physician and caregivers (Butler, 2014; Charles et al., 1999; Fiks et al., 2011; Lipstein, Dodds, & Britto, 2014; Lipstein, Brinkman, & Britto, 2012). Some studies have provided initial evidence of the efficacy of interventions promoting shared decision-making in the context of childhood ADHD (Brinkman et al., 2013; Chow, Sciberras, Gillam, Green, & Efron, 2013; Davis, Claudius, Palinkas, Wong, & Leslie, 2012). If the current study is replicated

in studies with greater statistical power, then this would provide further theoretical basis of the importance of establishing effective shared decision-making interventions.

The current study examined caregiver predictors of adherence to ADHD medication for school-aged children. Findings are similar to other ADHD medication adherence studies and the general pediatric adherence literature in several ways. First, higher poverty level and lower level of caregiver education were found to be associated with lower adherence. Similar associations between measures of socioeconomic status and adherence have been documented in studies specific to ADHD (e.g., Ibrahim, 2002) and other chronic conditions (e.g., Brownbridge & Fielding, 1994; Radius et al., 1978; Rapoff, Belmont, Lindsley, & Olson, 2005). However, these associations have not always been found in ADHD-specific studies (e.g., Gau et al., 2006; Johnston & Fine, 1993). Second, longer treatment duration (i.e., number of days included in MPR) was associated with lower adherence, which has also been demonstrated in other chronic conditions (e.g., Brownbridge & Fielding, 1994; Kovacs, Goldston, Obrosky, & Iyengar, 1992; Rapoff, et al., 2002).

Third, this study inadvertently focused solely on CNS medications as this was the only medication class prescribed to children. Gajria and colleagues (2014) noted the preponderance of studies on CNS medications only. Fourth, caregiver attitudes or beliefs were not found to be significantly related to medication adherence. While it would be premature to conclude that these variables are not associated with adherence to ADHD medication, it is not unusual for attitudes or beliefs to not account for significant variance in health-related behaviors (Clark & Houle, 2009; Janz & Becker, 1984; Rapoff, 2010). The current study did not find the often-reported improvement in adherence associated with long-acting CNS or once daily medications (Chou et al., 2009; Gajria et al., 2014; Gau et al., 2006; Rapoff, 2010).

Methodological Considerations

Limitations. While the current study is preliminary in nature, results must be considered in context of several limitations. First, the small sample size limits the power of the study and the generalizability of results. It is unclear whether support for the study hypothesis was not found because it truly does not exist or if the amount of available data was too small to find an effect. The large percent of families approached who were ineligible to participate (i.e., 67.88%) also limits the conclusions that may be drawn about the population of children with ADHD. Furthermore, all but one participant was a female caregiver, which perpetuates the lack of male caregivers in similar studies (Singh, 2003). Second, while this study reported information on whether child was currently receiving mental health treatment, we are not able to suggest how this may influence caregiver's decisions regarding ADHD medication.

Strengths. The current study has improved on previous studies in several ways. First, it was specifically designed to examine adherence to ADHD medications. Several studies were initially designed to evaluate treatment outcome and subsequently included investigation of medication adherence (e.g., Faraone et al., 2007; Gau et al., 2006). Second, the current study was not solely retrospective as several previous studies have been (e.g., Atzori, Usala, Carucci, Danjou, & Zuddas, 2009; Olfson, Marcus, & Wan, 2009; Winterstein et al., 2008) and included relatively adequate follow-up on medication adherence ($M = 164.45$, $Mdn = 194.00$, $SD = 100.01$). Third, it did not include any analog methodology as others have (e.g., Jiang et al., 2014). Fourth, the current study included multiple measures of adherence (Quittner et al., 2008; Rapoff, 2010), and accounted for planned drug holidays (Faraone et al., 2007; Rapoff, 2010). Fifth, the current study was theory-driven with an a priori hypothesis, and was designed to inform clinical practice. While the current study has been explicative in nature (i.e., clarifies relationships among variables associated with poor adherence to ADHD medication), it also

emphasized integration with intervention research and clinical utility of results (Roberts, 1992; Roberts, McNeal, Randall, & Roberts, 1996). Finally, the study included data regarding presence and severity of ADHD symptoms and comorbid disorders.

Future Directions

Recruitment. Difficulty recruiting for the current study led to learning several lessons that may improve future efforts. First, while a “clean” sample meeting several eligibility criteria is appealing, it may not be necessary in studies of adherence outcomes rather than treatment outcomes. For example, we postulated that caregivers that have experienced medication switching, especially when due to adverse effects, may have attitudes or beliefs that differ from caregivers who are on their first ADHD medication trial. However, the current state of the literature is such that we know little about the relationship between caregivers’ attitudes or beliefs and ADHD medication adherence in general. Thus, it may be premature to attempt to delineate these variables between groups of caregivers especially given potentially high rates of medication switching (3.7% to 59%; Gajria et al., 2014). Second, while the current study included several strategies for minimizing attrition (including enrollment refusal), incorporating specific additional strategies may be beneficial (Karlson & Rapoff, 2007). For example, providing participant incentives and minimizing participant burden especially by incorporating data collection into routine clinic visits appear to be promising. Of note, the majority of participants enrolled in the current study were recruited from a primary care location that readily allowed research personnel to be present in clinic. Nevertheless, time and concerns regarding clinic flow remained a barrier to completing study measures during the clinic appointment when families were initially approached about study participation. Third, while research databases such as the Pioneers RPR used in the current study, show promise as a recruitment tool, they

may be a less appropriate source for studies on “controversial” topics such as ADHD medication. The majority (67%) of families who declined participation were approached via the RPR. Many caregivers were not familiar with the registry and did not recall signing up for it. Furthermore, several caregivers made statements such as, “I’m not interested in anything that has to do with medicating my child.”

Measurement considerations. Future studies should continue to include multiple measures of adherence. Studies with a larger sample size (e.g., ≥ 120 participants) may be designed to use higher linear modeling to examine convergence between multiple measures of adherence. Future studies may also consider using a measure of functional impairment that provides outcomes that are continuous as opposed to ordinal (e.g., Fabiano et al., 2006). This measure may be used in addition to a symptom rating scale, such as VADPRS, to allow for more thorough assessment of the relationship between functional impairment and medication adherence. The Medication Recommendation VAS appears to be a promising measure of caregivers’ perception of doctors’ medication recommendations and may continue to be used in future studies. Given a larger sample size, it is likely this VAS will be normally distributed, which would allow for more powerful statistical analyses. While attitudes and beliefs may play a role in medication adherence, future studies should incorporate measures of barriers to adherence as these behavioral constructs have been found to be the most robust predictor across studies of the HBM (Becker, 1974; Janz & Becker, 1984; Rapoff, 2010).

Summary and Conclusions

Childhood ADHD is a significant public health issue as it is a disorder with a high prevalence and negative consequences (Visser et al., 2014). Well-established psychosocial and pharmacological treatments are available. However, approximately 30% of families prescribed

an ADHD medication may not fill it (Demidovich et al., 2011). Those who initiate medication commonly discontinue use within six months or have poor adherence (Gajria et al., 2014). The work of researchers, clinicians, and public health administrators alike may be improved by further understanding of the complex relationships between caregiver and child/adolescent attitudes, beliefs, and behaviors associated with initiating and adhering to an ADHD medication.

References

- Abikoff, H. B., Jensen, P. S., Arnold, L. L. E., Hoza, B., Hechtman, L., Pollack, S., . . .
- Wigal, T. (2002). Observed classroom behavior of children with ADHD: Relationship to gender and comorbidity. *Journal of Abnormal Child Psychology*, *30*, 349-359.
- Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for the ASEBA School-Age Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Adams, C. D., Dreyer, M. L., Dinakar, C., & Portnoy, J. M. (2004). Pediatric asthma: A look at adherence from the patient and family perspective. *Current Allergy and Asthma Reports*, *4*, 425-432.
- Ahmed, R., McCaffery, K. J., & Aslani, P. (2013). Factors influencing parental decision making about stimulant treatment for attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology*, *23*(3), 163-178. doi: 10.1089/cap.2012.0087
- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliff, NJ: Prentice-Hall.
- Allen, A. J., Kurlan, R. M., Gilbert, D. L., Coffey, B. J., Linder, S. L., Lewis, D. W., . . .
- Spencer, T. J. (2005). Atomoxetine treatment in children and adolescents with ADHD and comorbid tic disorders. *Neurology*, *65*, 1941-1949.
- American Academy of Child and Adolescent Psychiatry Work Group on Quality Issues (2007). Practice parameter for the assessment and treatment of children and adolescents with attention-deficit/hyperactivity disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, *46*(7), 894-921. doi: 10.1097/chi.0b013e318054e724

- American Academy of Pediatrics, Subcommittee on Attention-Deficit/Hyperactivity Disorder, Steering Committee on Quality Improvement and Management. (2011). ADHD: Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics*, *128*, 1007-1022. doi: 10.1542/peds.2011-2654
- American Academy of Pediatrics and National Initiative for Children's Healthcare Quality. (2002). *Caring for children with ADHD: A resource toolkit for clinicians*.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- American Psychiatric Association (2012). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Angold, A., & Costello, E. J. (1993). Depressive comorbidity in children and adolescents: Empirical, theoretical, and methodological issues. *American Journal of Psychiatry*, *150*(12), 1779-1791.
- Angold, A., Costello, J., Farmer, E. M. Z., Burns, B. J., & Erkanli, A. (1999). Impaired but undiagnosed. *Journal of American Academy of Child and Adolescent Psychiatry*, *38*(2), 129-137. doi: 0890-8567/99/3802-0129/\$03.00/0
- APA Working Group on Psychoactive Medications for Children and Adolescents. (2006). *Report of the Working Group on Psychoactive Medications for Children and Adolescents. Psychopharmacological, psychosocial, and combined interventions for childhood disorders: Evidence base, contextual factors, and future directions*. Washington, DC: American Psychological Association.

- Atzori, P., Usala, T., Carucci, S., Danjou, F., & Zuddas, A. (2009). Predictive factors for persistent use and compliance of immediate-release methylphenidate: A 36-month naturalistic study. *Journal of Child and Adolescent Psychopharmacology*, *19*(6), 673-681. doi: 10.1089/cap.2008.0146
- Bagwell, C. L., Molina, B. S. G., Pelham, W. E., & Hoza, B. (2001). Attention-deficit hyperactivity disorder and problems in peer relations: Predictions from childhood to adolescence. *Journal of the American Academy of Child and Adolescent Psychiatry*, *40*(11), 1285-1292.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Bandura, A. (1992). Exercise of personal agency through the self-efficacy mechanism. In R. Schwarzer (Ed.), *Self-efficacy: Thought control of action* (pp. 3-38). Washington, DC: Hemisphere.
- Bandura, A. (1994). Social cognitive theory and exercise of control over HIV infection. In R. J. DiClemente & J. L. Peterson (Eds.), *Preventing AIDS: Theories and methods of behavioral interventions* (pp. 1-20). New York: Plenum.
- Barbarese, W. J., Katusic, S. K., Colligan, R. C., Weaver, A. L., Leibson, C. L., & Jacobsen, S. J. (2006). Long-term stimulant medication treatment of attention-deficit/hyperactivity disorder: Results from a population-based study. *Journal of Developmental and Behavioral Pediatrics*, *27*(1), 1-10. doi: 0196-206X/06/2701-0001
- Barkley, R. A. (1997). *Defiant children: A clinician's manual for assessment and parent training* (2nd ed.). New York, NY: Guilford Press.

- Bauman, L. (2000). A patient-centered approach to adherence: Risks for nonadherence. In D. Drotar (Ed.), *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions* (pp. 71-93). Mahwah, NJ: Lawrence Erlbaum Associates.
- Becker, M. H. (1974). The health belief model and personal health behavior. *Health Education Monographs*, 2, 324-508.
- Becker, S. P., Langberg, J. M., Vaughn, A. J., & Epstein, J. N. (2012). Clinical utility of the Vanderbilt ADHD Diagnostic Parent Rating Scale comorbidity screening scales. *Journal of Developmental and Behavioral Pediatrics*, 33, 221-228.
- Bennett, D. S., Power, T. J., Rostain, A. L., & Carr, D. E. (1996). *Journal of Pediatric Psychology*, 21(5), 643-657.
- Biederman, J., Ball, S. W., Monuteaux, M. C., Mick, E., Spencer, T. J., McCreary, M., ... Faraone, S. V. (2008). New insights into the comorbidity between ADHD and major depression in adolescent and young adult females. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(4), 426-434. doi: 10.1097/CHI.0b013e31816429d3
- Biederman, J., Faraone, S. V., Keenan, K., Benjamin, J., Krifcher, B., Moore, C., ... Tsuang, M. T. (1992). Further evidence for family-genetic risk factors in attention deficit hyperactivity disorder. *Archives of General Psychiatry*, 49, 728-738.
- Biederman, J., Faraone, S., Milberger, S., Guite, J., Mick, E., Chen, L., ... Perrin, J. (1996). A prospective 4-year follow-up study of attention-deficit hyperactivity and related disorders. *Archives of General Psychiatry*, 53(5), 437-446. doi: 10.1001/archpsyc.1996.01830050073012

- Biederman, J., Kwon, A., Aleardi, M., Chouinard, V., Marino, T., Cole, H., ... Faraone, S. V. (2005). Absence of gender effects on attention deficit hyperactivity disorder: Findings in nonreferred subjects. *American Journal of Psychiatry*, *162*, 1083-1089.
- Biederman, J., Mick, E., Faraone, S. V., Braaten, E., Doyle, A., Spencer, T., ... Johnson, M. A. (2002). Influence of gender on attention deficit hyperactivity disorder in children referred to a psychiatric clinic. *American Journal of Psychiatry*, *159*, 36-42.
- Biederman, J., Newcorn, J., & Sprich, S. (1991). Comorbidity of attention-deficit hyperactivity disorder with conduct, depressive, anxiety, and other disorders. *American Journal of Psychiatry*, *148*(5), 564-577.
- Bloom, B., Cohen, R. A., & Freeman, G. (2010). Summary health statistics for U.S. children: National Health Interview Survey, 2009. National Center for Health Statistics. *Vital Health Statistics*, *10*(247), 1-82.
- Bond, G. G., Aiken, L. S., & Somerville, S. C. (1992). The health belief model and adolescents with insulin-dependent diabetes mellitus. *Health Psychology*, *11*(3), 190-198.
- Brinkman, W. B., Majcher, J. H., Poling, L. M., Shi, G., Zender, M. Sucharew, H., ... Epstein, J. N. (2013). Shared decision-making to improve attention-deficit hyperactivity disorder care. *Patient Education and Counseling*, *93*, 95-101. doi: 10.1016/j.pec.2013.04.009
- Brinkman, W. B., Sherman, S. N., Zmitrovich, A. R., Visscher, M. O., Crosby, L. E., Phelan, K. J., & Donovan, E. F. (2009). Parental angst making and revisiting decisions about treatment of attention-deficit/hyperactivity disorder. *Pediatrics*, *124*, 580-589. doi: 10.1542/peds.2008-2569
- Brinkman, W. B., Sherman, S. N., Zmitrovich, A. R., Visscher, M. O., Crosby, L. E., Phelan, K. J., & Donovan, E. F. (2012). In their own words: Adolescent views on ADHD and their evolving role managing medication. *Academic Pediatrics*, *12*(1), 53-61.

- Brito, A., Grant, R., Overholt, S., Aysola, J., Pino, I., Spalding, S. H., ... Redlener, I. (2008). The enhanced medical home: The pediatric standard of care for medically underserved children. *Advances in Pediatrics, 55*, 9-28.
- Brook, D. W., Brook, J. S., Zhang, C., & Koppel, J. (2010). Association between attention-deficit/hyperactivity disorder in adolescence and substance use disorders in adulthood. *Archives of Pediatrics and Adolescent Medicine, 164*(10), 930-934.
- Brown, R. T., Borden, K. A., Wynne, M. E., Spunt, A. L., & Clingerman, S. R. (1987). Compliance with pharmacological and cognitive treatments for attention deficit disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 26*(4), 521-526.
- Brownbridge, G., & Fielding, D. M. (1994). Psychosocial adjustment and adherence to dialysis treatment regimes. *Pediatric Nephrology, 8*, 744-749.
- Bruchmüller, K., Margraf, J., & Schneider, S. (2012). Is ADHD diagnosed in accord with diagnostic criteria? Overdiagnosis and influence of client gender on diagnosis. *Journal of Consulting and Clinical Psychology, 80*(1), 128-138. doi: 10.1037/a0026582
- Bush, P. J., & Iannotti, R. J. (1990). A children's health belief model. *Medical Care, 28*(1), 69-86.
- Bussing, R., & Gary, F. A. (2001). Practice guidelines and parental ADHD treatment evaluations: Friends or foes? *Harvard Review of Psychiatry, 9*, 223-233.
- Butler, A. M. (2014). Shared decision-making, stigma, and child mental health functioning among families referred for primary care-located mental health services. *Families, Systems, & Health, 32*(1), 115-121. doi: 10.1037/fsh0000004

- Chacko, A., Newcorn, J. H., Feirsen, N., & Uderman, J. Z. (2010). Improving medication adherence in chronic pediatric health conditions: A focus on ADHD in youth. *Current Pharmaceutical Design, 16*, 2416-2423. doi: 1381-6128/10
- Charach, A., Gajaria, A., Skyba, A., & Chen, S. (2008). Documenting adherence to psychostimulants in children with ADHD. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 17*(3), 131-136.
- Charach, A., Ickowicz, A., & Schachar, R. (2004). Stimulant treatment over five years: Adherence, effectiveness, and adverse effects. *Journal of the American Academy of Child and Adolescent Psychiatry, 43*(5), 559-567.
- Charach, A., Skyba, A., Cook, L., & Antle, B. J. (2006). Using stimulant medication for children with ADHD: What do parents say? A brief report. *Journal of Canadian Academy of Child and Adolescent Psychiatry, 15*(2), 75-83.
- Charach, A., Yeung, E., Climans, T., & Lillie, E. (2011). Childhood attention-deficit/hyperactivity disorder and future substance use disorders: Comparative meta-analyses. *Journal of the American Academy of Child and Adolescent Psychiatry, 50*(1), 9-21. doi: 10.1016/j.jaac.2010.09.019
- Charach, A., Yeung, E., Volpe, T., Goodale, T. & dosReis, S. (2014). Exploring stimulant treatment in ADHD: Narratives of young adolescents and their parents. *BMC Psychiatry, 14*, 110-130. doi: 10.1186/1471-244X-14-110
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science & Medicine, 44*(5), 681-692. doi: 0277-9536/97

- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*, *49*, 651-661. doi: 0277-9536/99
- Chou, W., Chou, M., Tzang, R., Hsu, Y., Gau, S. S., Chen, S., ... Cheng, H. (2009). Better efficacy for the osmotic release oral system methylphenidate among poor adherents to immediate-release methylphenidate in the three ADHD subtypes. *Psychiatry and Clinical Neurosciences*, *63*, 167-175. doi: 10.1111/j.1440-1819.2009.01937.x
- Chow, S. J., Sciberras, E., Gillam, L. H., Green, J., & Efron, D. (2013). Paediatricians' decision making about prescribing stimulant medications for children with attention-deficit/hyperactivity disorder. *Child: Care, Health, and Development*, *40*, 3, 301-308. doi: 10.1111/cch.12036
- Chronis-Tuscan, A., Molina, B. S. G., Pelham, W. E., Applegate, B., Dahlke, A., Overmyer, M., Lahey, B. B. (2010). Very early predictors of adolescent depression and suicide attempts in children with attention-deficit/hyperactivity disorder. *Archives of General Psychiatry*, *67*(10), 1044-1051.
- Clark, N. M., & Houle, C. R. (2009). Theoretical models and strategies for improving disease management by patients. In S. A. Shumaker, J. K. Ockene, & K. A. Riekert (Eds.), *The Handbook of Health Behavior Change* (3rd ed., pp. 19-37).
- Coghill, D. (2010). The impact of medications on quality of life in attention-deficit hyperactivity disorder: A systematic review. *CNS Drugs*, *24*(10), 843-866.

- Coghill, D., Danckaerts, M., Sonuga-Barke, E., Sergeant, J., & The ADHD European Guidelines Group. (2009). Practitioner Review: Quality of life in child mental health - conceptual challenges and practical choices. *Journal of Child Psychology and Psychiatry*, 50(5), 544-561. doi: 10.1111/j.1469-7610.2009.02008.x
- Coghill, D., & Seth, S. (2011). Do the diagnostic criteria for ADHD need to change? Comments on the preliminary proposals of the DSM-5 ADHD and Disruptive Behavior Disorders Committee. *European Child & Adolescent Psychiatry*, 20, 75-81. doi: 10.1007/s00787-010-0142-4
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155-159.
- Collett, B. R., Ohan, J. L., Myers, K. M. (2003). Ten-year review of rating scales. V: Scales assessing attention-deficit/hyperactivity disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42, 1015-1037.
- Coletti, D. J., Pappadopulos, E., Katsiotas, N. J., Berest, A., Jensen, P. S., & Kafantaris, V. (2012). Parent perspectives on the decision to initiate medication treatment of attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology*, 22(3), 1-12. doi: 10.1089/cap.2011.0090
- Corkum, P., Rimer, P., & Schachar, R. (1999). Parental knowledge of attention-deficit hyperactivity disorder and opinions of treatment options: Impact on enrollment and adherence to a 12-month treatment trial. *Canadian Journal of Psychiatry*, 44, 1043-1048.
- Cramer, J. A. (1995). Microelectronic systems for monitoring and enhancing patient compliance with medication regimens. *Drugs*, 49(3), 321-327.
- Cramer, J. A., Roy, A., Burrell, A., Fairchild, C. J., Fuldeore, M. J., Ollendorf, D. A., & Wong, P. K. (2008). Medication compliance and persistence: Terminology and definitions. *Value in Health*, 11(1), 44-47. doi: 10.1111/j.1524-4733.2007.00213.x

- Danckaerts, M., Sonuga-Barke, E. J. S., Banaschewski, T., Buitelaar, J., Dopfner, M., Hollis, C., . . . Coghill, D. (2010). The quality of life of children with attention deficit/hyperactivity disorder: a systematic review. *European Child & Adolescent Psychiatry, 19*(2), 83-105. doi: 10.1007/s00787-009-0046-3
- Davis, C. C., Claudius, M., Palinkas, L. A., Wong, J. B., & Leslie, L. K. (2012). Putting families in the center: Family perspectives on decision making and ADHD and implications for ADHD care. *Journal of Attention Disorders, 16*, 675-684. doi: 10.1177/1087054711413077
- Daviss, W. B., & Diler, R. (2012). Does comorbid depression predict subsequent adverse life events in youth with attention-deficit/hyperactivity disorders? *Journal of Child and Adolescent Psychopharmacology, 22*(1), 65-71. doi: 10.1089/cap.2011.0046
- Deaton, A. V. (1985). Adaptive noncompliance in pediatric asthma: The parent as expert. *Journal of Pediatric Psychology, 10*(1), 1-14.
- Demidovich, M., Kolko, D. J., Bukstein, O. G., & Hart, J. (2011). Medication refusal in children with oppositional defiant disorder or conduct disorder and comorbid attention-deficit/hyperactivity disorder: Medication history and clinical correlates. *Journal of Child and Adolescent Psychopharmacology, 21*(1), 57-66. doi: 10.1089/cap.2010.0001
- Diemer, M.A., Mistry, R., Wadsworth, M.E., López, I. & Reimers, F. (2012). Best practices in conceptualizing and measuring social class in psychological research. *Analyses of Social Issues and Public Policy, 0*(0), 1-37. doi: 10.1111/asap.12001
- DiMatteo, M. R., Giordani, P. J., Lepper, H. S., & Croghan, T. W. (2002). Patient adherence and medical treatment outcomes: A meta-analysis. *Medical Care, 40*(9), 794-811.

- Dirks, J. F., & Kinsman, R. A. (1982). Nondichotomous patterns of medication usage: The yes-no fallacy. *Clinical Pharmacology of Therapeutics*, *31*(4), 413-417.
- dosReis, S., Barksdale, C. L., Sherman, A., Maloney, K., & Charach, A. (2010). Stigmatizing experiences of parents of children with a new diagnosis of ADHD. *Psychiatric Services*, *61*, 811-816.
- dosReis, S., Zito, J. M., Safer, D. J., Soeken, K. L., Mitchell, J. W., & Ellwood, L. C. (2003). Parental perceptions and satisfaction with stimulant medication for attention-deficit/hyperactivity disorder. *Journal of Developmental and Behavioral Pediatrics*, *24*, 155-162.
- Dunbar- Jacob, J., & Schlenk, E. (2001). Patient Adherence to Treatment Regimen. In A. Baum, A. Revenson, & J. E. Singer (Eds.), *Handbook of Health Psychology* (pp. 571-580). Mahwah, NJ: Lawrence Erlbaum Associates.
- DuPaul, G.J., Power, T.J., Anastopoulos, A.D., & Reid, R. (1998). *ADHD Rating Scale-IV: Checklists, norms, and clinical interpretation*. New York: Guilford Press.
- Epstein, L. H., & Cluss, P. A. (1982). A behavioral medicine perspective on adherence to long-term medical regimens. *Journal of Consulting and Clinical Psychology*, *50*(6), 950-971.
- Evans, S. W., & Youngstrom, E. A. (2006). Evidence-based assessment of attention-deficit/hyperactivity disorder: Measuring outcomes. *Journal of the American Academy of Child and Adolescent Psychiatry*, *45*(9), 1132-1137. doi: 10.1097/01.chi.0000228355.23606.14

- Fabiano, G. A., Pelham, W. E., Waschbusch, D. A., Gnagy, E. M., Lahey, B. B., Chronis, A. M. ... Burrows-MacLean (2006). A practical measure of impairment: Psychometric properties of the Impairment Rating Scale in samples of children with attention deficit hyperactivity disorder and two school-based samples. *Journal of Clinical Child and Adolescent Psychology*, 35(3), 369-385. doi: 10.1207/s15374424jccp3503_3
- Faraone, S. V., Biederman, J., & Zimmerman, B. (2007). An analysis of patient adherence to treatment during a 1-year, open-label study of OROS methylphenidate in children with ADHD. *Journal of Attention Disorders*, 11(2), 157-166. doi: 10.1177/1087054706295663
- Farmer, K. C. (1999). Methods for measuring and monitoring medication regimen adherence in clinical trials and clinical practice. *Clinical Therapeutics*, 21(6), 1074-1090.
- Fiks, A. G., Hughes, C. C., Gafen, A., Guevara, J. P., & Barg, F. K. (2011). Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. *Pediatrics*, 127, e188-e196. doi: 10.1542/peds.2010-1510
- Fiks, A. G., Mayne, S., DeBartolo, E., Power, T. J., & Guevara, J. P. (2013). Parental preferences and goals regarding ADHD treatment. *Pediatrics*, 132, 692-702. doi: 10.1542/peds.2013-0152
- Fishbein, M. (1980). A theory of reasoned action: Some applications and implications. In H. Howe & M. Page (Eds.), *Nebraska Symposium on Motivation, 1979* (pp. 65-116). Lincoln: University of Nebraska Press.
- Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention and behavior: An introduction to theory and research*. Boston: Addison-Wesley.

- Flory, K., Molina, B. S. G., Pelham, W. E., Gnagy, E., & Smith, B. (2006). Childhood ADHD predicts risky sexual behavior in young adulthood. *Journal of Clinical Child & Adolescent Psychology, 35*(4), 571-577. doi: 10.1207/s15374424jccp3504_8
- Frazier, J. A., Biederman, J., Bellorde, C. A., Garfield, S. B., Geller, D. A., Coffey, B. J., & Faraone, S. V. (2001). Should the diagnosis of Attention-Deficit/ Hyperactivity disorder be considered in children with Pervasive Developmental Disorder? *Journal of Attention Disorders, 4*, 203-211. doi: 10.1177/108705470100400402
- Frazier, T. W., Youngstrom, E. A., Glutting, J. J., & Watkins, M. W. (2007). ADHD and achievement: Meta-analysis of the child, adolescent, and adult literatures and a concomitant study with college students. *Journal of Learning Disabilities, 40*(1), 49-65.
- Freeman, R. D., Fast, D. K., Burd, L., Kerbeshian, J., Robertson, M. M., & Sandor, P. (2000). An international perspective on Tourette syndrome: Selected findings from 3500 individuals in 22 countries. *Developmental Medicine & Child Neurology, 42*, 436-447.
- Gajria, K., Lu, M., Sikirica, V., Greven, P., Zhong, Y., Qin, P., & Xie, J. (2014). Adherence, persistence, and medication discontinuation in patients with attention-deficit/hyperactivity disorder: A systematic review. *Neuropsychiatric Disease and Treatment, 10*, 1543-1569. doi: 10.2147/NDT.S65721
- Gau, S. S. F., Shen, H. Y., Chou, M. C., Tang, C. S., Chiu, Y. N., & Gau, C. S. (2006). Determinants of adherence to methylphenidate and the impact of poor adherence on maternal and family measures. *Journal of Child and Adolescent Psychopharmacology, 16*(3), 286-297.
- Gershon, J. (2002). A meta-analytic review of gender differences in ADHD. *Journal of Attention Disorders, 5*(3), 143-154.

- Goldman, L. S., Genel, M., Bezman, R. J., & Slanetz, P. J. (1998). Diagnosis and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *The Journal of the American Medical Association*, *279*, 1100-1107. doi: 10.1037//0022-006X.68.3.489
- Goldstein, S., & Schwebach, A. J. (2004). The comorbidity of Pervasive Developmental Disorder and Attention Deficit Hyperactivity Disorder: Results of a retrospective chart review. *Journal of Autism and Developmental Disorders*, *34*(3), 329-339. doi: 10.1023/B:JOUR.2004.0600.0329.0
- Graves, M. M., Adams, C. D., Bender, J. A., Simon, S., & Portnoy, J. M. (2007). Volitional nonadherence in pediatric asthma: Parental report of motivating factors. *Current Allergy and Asthma Reports*, *7*, 427-432.
- Graves, M. M., Roberts, M. C., Rapoff, M. A., & Boyer, A. (2010). The efficacy of adherence interventions for chronically ill children: A meta-analytic review. *Journal of Pediatric Psychology*, *35*(4), 368-382. doi: 10.1093/jpepsy/jsp072
- Hansen, D. L., & Hansen, E. H. (2006). Caught in a balancing act: Parents' dilemmas regarding their ADHD child's treatment with stimulant medication. *Qualitative Health Research*, *16*, 1267-1285. doi: 10.1177/1049732306292543
- Harpur, R. A., Thompson, M., Daley, D., Abikoff, H., & Sonuga-Barke, E. J. S. (2008). The attention-deficit/hyperactivity disorder medication-related attitudes of patients and their parents. *Journal of Child and Adolescent Psychopharmacology*, *18*(5), 461-473. doi: 10.1089/Cap.2008.023

- Harrison, J. R., Vannest, K. J., & Reynolds, C. R. (2011). Behaviors that discriminate ADHD in children and adolescents: Primary symptoms, symptoms of comorbid conditions, or indicators of functional impairment? *Journal of Attention Disorders, 15*(2), 147-160. doi: 10.1177/1087054709356170
- Haynes, R. B., Sackett, D. L., Gibson, E. S., Taylor, D. W., Hackett, B. C., Roberts, R. S. (1976). Improvement of medication compliance in uncontrolled hypertension. *The Lancet, 97*, 1265-1268.
- Horne, R. (2006). Compliance, adherence, and concordance: Implications for asthma treatment. *Chest, 130*(1 Suppl), 65S-72S.
- Hoza, B. (2007). Peer functioning in children with ADHD. *Journal of Pediatric Psychology, 32*(6), 655-663. doi: 10.1093/jpepsy/jsm024
- Hoza, B., Johnston, C., Pillow, D. R., & Ascough, J. C. (2006). Predicting treatment response for childhood attention-deficit/hyperactivity disorder: Introduction of a heuristic model to guide research. *Applied and Preventive Psychology, 11*, 215-229. doi: 10.1016/j.appsy.2005.11.001
- Hoza, B., Kaiser, N.M., & Hurt, E. (2007). Multimodal treatments for childhood attention-deficit/hyperactivity disorder: Interpreting outcomes in the context of study designs. *Clinical, Child, & Family Psychology Review, 10*, 318–334. doi: 10.1002/jclp
- Hoza, B., Mrug, S., Gerdes, A. C., Hinshaw, S. P., Bukowski, W. M., & Gold, J. A. (2005). What aspects of peer relationships are impaired in children with attention-deficit/hyperactivity disorder? *Journal of Consulting and Clinical Psychology, 73*(3), 411-423. doi: 10.1037/0022-006x.73.3.411

- Hoza, B., Owens, J. S., Pelham, W. E., Swanson, J. M., Conners, C. K., Hinshaw, S. P., ... Kraemer, H. C. (2000). Parent cognitions as predictors of child treatment response in attention-deficit/hyperactivity disorder. *Journal of Abnormal Child Psychology*, 28(6), 569-583. doi: 0091-0627/00/1200-0569\$18.00/0
- Hughes, D. (2007). When drugs don't work: Economic assessment of enhancing compliance with interventions supported by electronic monitoring devices. *Pharmacoeconomics*, 25(8), 621-635.
- Ibrahim, E. R. (2002). Rates of adherence to pharmacological treatment among children and adolescents with attention deficit hyperactivity disorder. *Human Psychopharmacology-Clinical and Experimental*, 17(5), 225-231. doi: 10.1002/Hup.406
- Jackson, D., & Peters, K. (2008). Use of drug therapy in children with attention deficit hyperactivity disorder (ADHD): Maternal views and experiences. *Journal of Clinical Nursing*, 17, 2725-2732. doi: 10.1111/j.1365-2702.2008.02444.x
- Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. *Health Education Quarterly*, 11, 1-47.
- Jensen, P. S., Arnold, L. E., Swanson, J. M., Vitiello, B., Abikoff, H. B., Greenhill, L. L., ... Hur, K. (2007). 3-year follow-up of the NIMH MTA study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(8), 989-1002. doi: 10.1097/chi.0b013e3180686d48
- Jensen, P. S., Hoagwood, K. E., Roper, M., Arnold, L. E., Odbert, C., Crowe, B. S. M., ... Wells, K. (2004). The services for children and adolescents-parent interview: Development and performance characteristics. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43(11), 1334-1344.

- Jiang, Y., Gurm, M., & Johnston, C. (2014). Child impairment and parenting self-efficacy in relation to mothers' views of ADHD treatments. *Journal of Attention Disorders, 18*, 532-541. doi: 10.1177/1087054712443412
- Johnston, C., & Fine, S. (1993). Methods of evaluating methylphenidate in children with attention deficit hyperactivity disorder: Acceptability, satisfaction, and compliance. *Journal of Pediatric Psychology, 18*(6), 717-730.
- Jones, D. E., Foster, E. M., & Conduct Problems Prevention Research Group. (2009). Service use patterns for adolescents with ADHD and comorbid conduct disorder. *The Journal of Behavioral Health Services & Research, 36*(4), 436-449.
- Kahana, S., Drotar, D., & Frazier, T. (2008). Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *Journal of Pediatric Psychology, 33*(6), 590-611. doi: 10.1093/jpepsy/jsm128
- Karolson, C. W., & Rapoff, M. A. (2009). Attrition in randomized controlled trials for pediatric chronic conditions. *Journal of Pediatric Psychology, 34*(7), 782-793. doi: 10.1093/jpepsy/jsn122
- Keiling, C., Kieling, R. R., Rohde, L. A., Frick, P. J., Moffitt, T., Nigg, J. T., ... Castellanos, F. X. (2010). The age at onset of attention deficit hyperactivity disorder. *The American Journal of Psychiatry, 167*(1), 14-16. doi: 10.1176/appi.ajp.2009.09060796
- Klein, R. G., Mannuzza, S., Ramos Olazagasti, M. A., Roizen, E., Hutchison, J. A., Lashua, E. C., & Castellanos, X. (2012). Clinical and functional outcome of childhood attention-deficit/hyperactivity disorder 33 years later. *Archives of General Psychiatry, 69*(12), 1295-1303. doi: 10.1001/archgenpsychiatry.2012.271

- Kovacs, M., Goldston, D., Obrosky, S., & Iyengar, S. (1992). Prevalence and predictors of pervasive noncompliance with medical treatment among youths with insulin-dependent diabetes mellitus. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31(6), 1112-1119.
- La Greca, A. M. (1990). Issues in adherence with pediatric regimens. *Journal of Pediatric Psychology*, 15(4), 423-436.
- Landgraf, J.M., Abetz, L.N., & Ware, J.E. (1999). *The CHQ users manual*. Boston, MA: Health Act.
- Landgraf, J. M., Rich, M., & Rappaport, L. (2002). Measuring quality of life in children with attention-deficit/hyperactivity disorder and their families - Development and evaluation of a new tool. *Archives of Pediatrics & Adolescent Medicine*, 156(4), 384-391.
- Lefever, G. B., Villers, M. S., Morrow, A. L., & Vaughn, S. E. (2002). Parental perceptions of adverse educational outcomes among children diagnosed and treated for ADHD: A call for improved school/provider collaboration. *Psychology in the Schools*, 39(1), 63-71.
- Leslie, L. K., Plemmons, D., Monn, A. R., & Palinkas, L. A. (2007). Investigating ADHD treatment trajectories: Listening to families' stories about medication use. *Journal of Developmental and Behavioral Pediatrics*, 28, 179-188.
- Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, 32, 246-258. doi: 10.1177/0272989X11421528
- Lipstein, E. A., Dodds, C. M., & Britto, M. T. (2014). Real life clinic visits do not match the ideals of shared decision making. *Journal of Pediatrics*, 165, 178-183. doi: 10.1016/j.jpeds.2014.03.042

- Liu, C., Robin, A. L., Brenner, S., & Eastman, J. (1991). Social acceptability of methylphenidate and behavior modification for treating attention deficit hyperactivity disorder. *Pediatrics*, 88, 560-565.
- Loe, I. M., & Feldman, H. M. (2007). Academic and educational outcomes of children with ADHD. *Journal of Pediatric Psychology*, 32(6), 643-654. doi: 10.1093/jpepsy/jsl054
- Maniadaki, K., Sonuga-Barke, E., & Kakouros, E. (2006). Adults' self-efficacy beliefs and referral attitudes for boys and girls with AD/HD. *European Child and Adolescent Psychiatry*, 15, 132-140. doi: 10.1007/s00787-005-0514-3
- Marcus, S. C., & Durkin, M. (2011). Stimulant adherence and academic performance in urban youth with attention-deficit/hyperactivity disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 50(5), 480-489. doi: 10.1016/j.jaac.2011.02.007
- Marcus, S. C., Wan, G. J., Kemner, J. E., & Olfson, M. (2005). Continuity of methylphenidate treatment for attention-deficit/hyperactivity disorder. *Archives of Pediatrics & Adolescent Medicine*, 159, 572-578.
- Masseti, G. M., Lahey, B. B., Pelham, W. E., Loney, J., Ehrhardt, A., Lee, S. S., & Kip, H. (2008). Academic achievement over 8 years among children who met modified criteria for attention-deficit/hyperactivity disorder at 4–6 years of age. *Journal of Abnormal Child Psychology*, 36, 399-410. doi: 10.1007/s10802-007-9186-4
- Matsui, D. (2000). Children's adherence to medication treatment. In D. Drotar (Ed.), *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions* (pp. 135-152). Hillsdale, NJ: Lawrence Erlbaum.

- Matza, L. S., Swensen, A. R., Flood, E. M., Secnik, K., & Leidy, N. K. (2004). Assessment of health-related quality of life in children: A review of conceptual, methodological, and regulatory issues. *Value in Health*, 7(1), 79-92.
- McConaughy, S. H., Volpe, R. J., Antshel, K. M., Gordon, M., & Eiraldi, R. B. (2011). Academic and social impairments of elementary school children with attention deficit hyperactivity disorder. *School Psychology Review*, 40(2), 200-225.
- McMahon, R. J., & Forehand, R. (2003). *Helping the noncompliant child: A clinician's guide to effective parenting* (2nd ed.). New York, NY: Guilford.
- Merikangas, K. R., He, J., Brody, D., Fisher, P. W., Bourdon, K., & Koretz, D. S. (2010). Prevalence and treatment of mental disorders among US children in the 2001-2004 NHANES. *Pediatrics*, 125, 75-81. doi:10.1542/peds.2008-2598
- Mick, E., Faraone, S. V., & Biederman, J. (2004). Age-dependent expression of attention-deficit/hyperactivity disorder symptoms. *Psychiatric Clinics of North America*, 27(2), 215-224.
- Miller, M. D., & Ferris, D. G. (1993). Measurement of subjective phenomena in primary care research: The visual analogue scale. *Family Practice Research Journal*, 13(1), 15-24.
- Miller, A. R., Lalonde, C. E., & McGrail, K. M. (2004). Children's persistence with methylphenidate therapy: A population-based study. *Canadian Journal of Psychiatry*, 49(11), 761-768.
- Millichap, J. G. (2010). *Attention deficit hyperactivity disorder handbook: A physician's guide to ADHD* (2nd ed.). New York, NY: Springer.

- Modi, A. C., Lim, C. S., Yu, N., Geller, D., Wagner, M. H., & Quittner, A. L. (2006). A multi-method assessment of treatment adherence for children with cystic fibrosis. *Journal of Cystic Fibrosis*, 5(3), 177-185.
- Molina, B. S. G., Flory, K., Hinshaw, S. P., Greiner, A. R., Arnold, L. E., Swanson, J. M., ... Wigal, T. (2007a). Delinquent behavior and emerging substance use in the MTA at 36 months: Prevalence, course, and treatment effects. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(8), 1028-1040.
- Molina, B. S. G., Pelham, W. E., Gnagy, E. M., Thompson, A. L., & Marshal, M. P. (2007b). Attention-deficit/hyperactivity disorder risk for heavy drinking and alcohol use disorder is age specific. *Alcoholism: Clinical and Experimental Research*, 31(4), 643-654. doi: 10.1111/j.1530-0277.2007.00349.x
- Mrug, S., Hoza, B., & Gerdes, A. C. (2001). Children with attention-deficit/hyperactivity disorder: Peer relationships and peer-oriented interventions. In C. A. Erdley & D. W. Nangle (Eds.). *The Role of Friendship in Psychological Adjustment: New Directions for Child and Adolescent Development* (pp. 51-77). San Francisco, CA: Jossey-Bass Inc.
- MTA Cooperative Group (1999). A 14-month randomized clinical trial of treatment strategies for attention-deficit/hyperactivity disorder. *Archives of General Psychiatry*, 56, 1073-1086.
- Murray-Close, D., Hoza, B., Hinshaw, S. P., Arnold, L. E., Swanson, J., Jensen, P. S., ... Wells, K. (2010). Developmental processes in peer problems of children with attention-deficit/hyperactivity disorder in The Multimodal Treatment Study of Children with ADHD: Developmental cascades and vicious cycles. *Development and Psychopathology*, 22, 785-802. doi: 10.1017/S0954579410000465

- National Institute of Mental Health. (2010). Mental health medications. Retrieved November 23, 2014, from <http://www.nimh.nih.gov/health/publications/mental-health-medications/index.shtml>
- Nijmeijer, J. S., Minderaa, R. B., Buitelaar, J. K., Mulligan, A., Hartman, C. A., & Hoekstra, P. J. (2008). Attention-deficit/hyperactivity disorder and social dysfunctioning. *Clinical Psychology Review, 28*(4), 692-708. doi: 10.1016/j.cpr.2007.10.003
- Olfson, M., Marcus, S., & Wan, G. (2009). Stimulant dosing for children with ADHD: A medical claims analysis. *Journal of the American Academy for Child and Adolescent Psychiatry, 48*(1), 51-59. doi: 10.1097/CHI.0b013e31818b1c8f
- Ollendick, T. H., Jarrett, M. A., Grills-Taquechel, A. E., Hovey, L. D., Wolff, J. C. (2008). Comorbidity as a predictor and moderator of treatment outcome in youth with anxiety, affective, attention deficit/hyperactivity disorder, and oppositional/conduct disorders. *Clinical Psychology Review, 28*, 1447-1471. doi:10.1016/j.cpr.2008.09.003
- Owens, J. S., Goldfine, M. E., Evangelista, N. M., Hoza, B., & Kaiser, N. M. (2007). A critical review of self-perceptions and the positive illusory bias in children with ADHD. *Clinical Child and Family Psychology Review, 10*(4), 335-351. doi: 10.1007/s10567-007-0027-3
- Pastor, P. N., & Reuben, C. A. (2008). Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004–2006. National Center for Health Statistics. *Vital Health Statistics, 10*(237), 1-14.
- Pelham, W. E., & Fabiano, G. A. (2001). Treatment of attention-deficit/hyperactivity disorder: The impact of comorbidity. *Clinical Psychology and Psychotherapy, 8*, 315-329. doi: 10.1002/cpp.312

- Pelham, W. E., & Fabiano, G. A. (2008). Evidence-based psychosocial treatments for attention-deficit/hyperactivity disorder. *Journal of Clinical Child and Adolescent Psychology, 37*(1), 184-214. doi: 10.1080/15374410701818681
- Pelham, W. E., Fabiano, G. A., & Massetti, G. M. (2005). Evidence-based assessment of attention deficit hyperactivity disorder in children and adolescents. *Journal of Clinical Child and Adolescent Psychology, 34*(3), 449-476. doi: 10.1207/s15374424jccp3403_5
- Pelham, W. E., Foster, E. M., & Robb, J. A. (2007). The economic impact of attention-deficit/hyperactivity disorder in children and adolescents. *Journal of Pediatric Psychology, 32*(6), 711-727. doi: 10.1093/jpepsy/jsm022
- Pelham, W. E., & Hoza, B. (1996). Intensive treatment: A summer treatment program for children with ADHD. In E. Hibbs & P. Jensen (Eds.) *Psychosocial treatments for child and adolescent disorders: Empirically based strategies for clinical practice* (pp. 311-340). New York, NY: APA Press.
- Pelham, W. E., Wheeler, T., & Chronis, A. (1998). Empirically supported psychosocial treatments for attention deficit hyperactivity disorder. *Journal of Clinical Child Psychology, 27*(2), 190-205. doi: 10.1207/s15374424jccp2702_6
- Polanczyk, G., Silva de Lima, M., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: A systematic review and metaregression analysis. *American Journal of Psychiatry, 164*, 942-948.
- Pringsheim, T., & Steeves, T. (2011). Pharmacological treatment for attention deficit hyperactivity disorder (ADHD) in children with comorbid tic disorders. *Cochrane Database of Systematic Reviews, 4*, 1-33. doi: 10.1002/14651858.CD007990.pub2

- Quittner, A. L., Modi, A. C., Lemanek, K. L., Ievers-Landis, C. E., & Rapoff, M. A. (2008). Evidence-based Assessment of Adherence to Medical Treatments in Pediatric Psychology. *Journal of Pediatric Psychology, 33*(9), 916-936. doi: doi:10.1093/jpepsy/jsm064
- Radius, S. M., Becker, M. H., Rosenstock, I. M., Drachman, R. H., Schuberth, K. C., & Teets, K. C. (1978). Factors influencing mothers' compliance with a medication regimen for asthmatic children. *Journal of Asthma Research, 15*(3), 133-149.
- Rand, C. S., & Wise, R. A. (1994). Measuring adherence to asthma medication regimens. *American Journal of Respiratory and Critical Care Medicine, 149*(2), S69-76.
- Rapoff, M. A. (2010). *Adherence to pediatric medical regimens* (2nd ed.). New York: Springer.
- Rapoff, M. A., Belmont, J. M., Lindsley, C. B., Olson, N. Y. (2005). Electronically monitored adherence to medications by newly diagnosed patients with juvenile rheumatoid arthritis. *Arthritis & Rheumatism, 53*(6), 905-910. doi: 10.1002/art.21603
- Rapoff, M. A., Belmont, J. M., Lindsley, C. B., Olson, N. Y., Moriss, J., & Padur, J. (2002). Prevention of nonadherence to nonsteroidal anti-inflammatory medications for newly diagnosed patients with juvenile rheumatoid arthritis. *Health Psychology, 21*(6), 620-623.
- Reynolds, C. R., & Kamphaus, R. W. (2004). *BASC-2: Behavior assessment system for children, second edition manual*. Circle Pines, MN: American Guidance Service.
- Riley, A.W., Forrest, C.B., Rebok, G.W., Starfield, B., Green, B.F., Robertson, J.A., & Friello, P. (2004a). The child report form of the CHIP–Child Edition: Reliability and validity. *Medical Care, 42*, 221–231.

- Riley, A.W., Forrest, C.B., Starfield, B., Rebok, G., Robertson, J.A., & Green, B.F. (2004b). The parent report form of the CHIP–Child Edition: Reliability and validity. *Medical Care, 42*, 210–220.
- Robb, J. A., Sibley, M. H., Pelham, W. E., Foster, E. M., Molina, B. S. G., Gnagy, E. M., & Kuriyan, A. B. (2011). The estimated annual cost of ADHD to the US education system. *School Mental Health, 3*, 169–177. doi: 10.1007/s12310-011-9057-6
- Roberts, M. C. (1992). Vale dictum: An editor’s view of the field of pediatric psychology and its journal. *Journal of Pediatric Psychology, 17*, 785-805.
- Roberts, M. C., McNeal, R. E., Randall, C. J., & Roberts, J. C. (1996). A necessary reemphasis on integrating explicative research with the pragmatics of pediatric psychology. *Journal of Pediatric Psychology, 21*(1), 107-114. doi: 10.1093/jpepsy/21.1.107
- Rosenstock, I. M. (1974). Historical origins of the Health Belief Model. *Health Education Monographs, 2*, 328- 335.
- Rostain, A. L., Power, T. J., & Atkins, M. C. (1993). Assessing parents’ willingness to pursue treatment for children with attention-deficit/hyperactivity disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 32*(1), 175-181.
- Rudd, P. (1993). The measurement of compliance: Medication taking. In N. A. Krasnegor, L. Epstein, S. B. Johnson, & S. J. Yaffe (Eds.), *Developmental aspects of health compliance behavior* (pp. 185-213). Hillsdale, NJ: Erlbaum.
- Rudd, P., Byyny, R. L., Zachary, V., LoVerde, M. E., Titus, C., Mitchell, W. D., & Marshall, G. (1989). The natural history of medication compliance in a drug trial: Limitations of pill counts. *Clinical Pharmacology & Therapeutics, 46*(2), 169-176.

- Satterfield, J. H., Faller, K. J., Crinella, F. M., Schell, A. M., Swanson, J. M., & Homer, L. D. (2007). A 30-year prospective follow-up study of hyperactive boys with conduct problems: Adult criminality. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(5), 601-610. doi: 10.1097/chi.0b013e318033ff59
- Shaw, M., Hodgkins, P., Caci, H., Young, S., Kahle, J., Woods, A. G., & Arnold, L. E. (2012). A systematic review and analysis of long-term outcomes in attention deficit hyperactivity disorder: Effects of treatment and non-treatment. *BMC Medicine, 10*(1), 99-114. doi: 10.1186/1741-7015-10-99
- Sibley, M. H., Pelham, W. E., Molina, B. S. G., Gnagy, E. M., Waschbusch, D. A., Biswas, A., ... Karch, K. M. (2011). The delinquency outcomes of boys with ADHD with and without comorbidity. *Journal of Abnormal Child Psychology, 39*, 21-32. doi: 10.1007/s10802-010-9443-9
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with Autism Spectrum Disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921-929. doi: 10.1097/CHI.0b013e318179964f
- Singh, I. (2003). Boys will be boys: Father's perspectives on ADHD symptoms, diagnosis, and drug treatment. *Harvard Review of Psychiatry, 11*, 308-316. doi: 10.1080/10673220390264221
- Spencer, T. J., Biederman, J., Coffey, B., Geller, D., Wilens, T., & Faraone, S. V. (1999). The 4-year course of tic disorders in boys with attention-deficit/hyperactivity disorder. *Archives of General Psychiatry, 56*, 842-847.

- Spencer, T. J., Biederman, J., & Mick, E. (2007). Attention-Deficit/Hyperactivity disorder: Diagnosis, lifespan, comorbidities, and neurobiology. *Journal of Pediatric Psychology, 32*(6), 631-642. doi: 10.1093/jpepsy/jsm005
- Steiner, J. F., & Prochazka, A. V. (1997). The assessment of refill compliance using pharmacy records: Methods, validity, and applications. *Journal of Clinical Epidemiology, 50*(1), 105-116. doi: 0895-4356/97
- Task Force on Promotion and Dissemination of Psychological Procedures (1995). Training in and dissemination of empirically-validated psychological treatments: Report and recommendations. *The Clinical Psychologist, 48*, 3-24.
- Taylor, M., O'Donoghue, T., Houghton, S. (2006). To medicate or not to medicate? The decision-making process of Western Australian parents following their child's diagnosis with attention deficit hyperactivity disorder. *International Journal of Disability Development and Education, 53*, 111-128.
- Thompson, A. L., Molina, B. S. G., Pelham, W. E., & Gnagy, E. M. (2007). Risky driving in adolescents and young adults with childhood ADHD. *Journal of Pediatric Psychology, 32*(7), 745-759. doi: 10.1093/jpepsy/jsm002
- Thiruchelvam, D., Charach, A., & Schachar, R. J. (2001). Moderators and mediators of long-term adherence to stimulant treatment in children with ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(8), 922-928.
- Tourette Syndrome Study Group (2002). Treatment of ADHD in children with tics: A randomized controlled trial. *Neurology, 58*, 527-536.

- Valo, S., & Tannock, R. (2010). Diagnostic instability of DSM–IV ADHD subtypes: Effects of informant source, instrumentation, and methods for combining symptom reports. *Journal of Clinical Child & Adolescent Psychology, 39*(6), 749-760. doi: 10.1080/15374416.2010.517172
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the pediatric quality of life Inventory™ Version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*(8), 800-812.
- Visser, S. N., Bitsko, R. H., Danielson, M. L., Perou, R., & Blumberg, S. J. (2010). Increasing prevalence of parent-reported attention-deficit/hyperactivity disorder among children – United States, 2003 and 2007. *Morbidity & Mortality Weekly Report, 59*(44), 1439-1443.
- Visser, S. N., Danielson, M. L., Bitsko, R. H., Holbrook, J. R., Kogan, M. D., Ghandour, R. M., ... Blumberg, S. J. (2014). Trends in the parent-report of health care provider-diagnosed and medicated attention-deficit/hyperactivity disorder: United States, 2003-2011. *Journal of American Academy of Child and Adolescent Psychiatry, 53*(1), 34-46. doi: 10.1016/j.jaac.2013.09.001
- Visser, S. N., Lesesne, C. A., & Perou, R. (2007). National estimates and factors associated with medication treatment for childhood attention-deficit/hyperactivity disorder. *Pediatrics, 119*, S99-S106. doi: 10.1542/peds.2006-2089O
- Vitulano, M. L., Fite, P. J., Wimsatt, A. R., Rathert, J. L., & Hatmaker, R. S. (2012). Gender differences in consequences of ADHD symptoms in a community-based organization for youth. *International Journal of Behavioral Development, 36*(2), 157-166. doi: 10.1177/0165025411430776

- von Polier, G. G., Vloet, T. D., & Herpertz-Dahlmann, B. (2012). ADHD and delinquency – A developmental perspective. *Behavioral Sciences and the Law*, *30*, 121-139. doi: 10.1002/bsl.2005
- Weiss, M.D., & Brooks, B.L. (2007). *Clinical normative data for the Weiss Functional Impairment Rating Scale*. American Academy of Child and Adolescent Psychiatry Annual Meeting, Boston.
- Wewers, M. E., & Lowe, N. K. (1990). A critical review of visual analogue scales in the measurement of clinical phenomena. *Research in Nursing and Health*, *13*(4), 227-236. doi: 10.1002/nur.4770130405
- Wheeler, J., & Carlson, C. L. (1994). The social functioning of children with ADD with hyperactivity and ADD without hyperactivity: A comparison of their peer relations and social deficits. *Journal of Emotional and Behavioral Disorders*, *2*(1), 2-12.
- WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from The World Health Organization. *Social Science & Medicine*, *41*(10), 1403-1409.
- Wigal (2009). Efficacy and safety limitations of attention-deficit/hyperactivity disorder pharmacotherapy in children and adults. *CNS Drugs*, *23*(Suppl 1), 21-31. doi: 1172-7047/09/0001-0021
- Wilens, T. E., Martelon, M. K., Joshi, G., Bateman, C., Fried, R., Petty, C., & Biederman, J. (2011). Does ADHD predict substance-use disorders? A 10-year follow-up study of young adults with ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry*, *50*(6), 543-553. doi: 10.1016/j.jaac.2011.01.021

- Willcutt, E. G., Nigg, J. T., Pennington, B. F., Solanto, M. V., Rohde, L. A., Tannock, R., ... Lahey, B. B. (2012). Validity of DSM-IV attention deficit/hyperactivity disorder symptom dimensions and subtypes. *Journal of Abnormal Psychology, 121*(4), 991-1010. doi: 10.1037/a0027347
- Winterstein, A. G., Gerhard, T., Shuster, J., Zito, J., Johnson, M., Liu, H. Z., & Saidi, A. (2008). Utilization of pharmacologic treatment in youths with attention deficit/hyperactivity disorder in medicaid database. *Annals of Pharmacotherapy, 42*(1), 24-31. doi: 10.1345/Aph.1k143
- Wolraich, M. L., Feurer, I. D., Hannah, J. N., Baumgaertel, A., & Pinnock, T. Y. (1998). Obtaining systematic teacher reports of disruptive behavior disorders utilizing DSM-IV. *Journal of Abnormal Child Psychology, 26*, 141-152.
- Wolraich, M. L., Lambert, W., Bickman, L., Simmons, T., Doffing, M. A., & Worley, K. (2004). Assessing the impact of parent and teacher agreement on diagnosing attention-deficit/hyperactivity disorder. *Journal of Developmental and Behavioral Pediatrics, 25*(1), 41-47. doi: 0196-206X/00/2501-0041
- Wolraich, M. L., Lambert, W., Doffing, M. A., Bickman, L., Simmons, T., & Worley, K. (2003). Psychometric properties of the Vanderbilt ADHD diagnostic parent rating scale in a referred population. *Journal of Pediatric Psychology, 28*, 559-568.
- World Health Organization. (1993). *ICD-10, the ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research*. Geneva: World Health Organization.
- World Health Organization (2003). *Adherence to long-term therapies: Evidence for action*. Geneva: Author.

Wroe, A. L. (2002). Intentional and unintentional nonadherence: A study of decision-making. *Journal of Behavioral Medicine*, 25(4), 355-372. doi: 0160-7715/02/0800-0355/0

Appendix A

Frontiers Research Participant Registry Permission Form

FRONTIERS: Heartland Institute for Clinical and Translational Research **Permission for Contact about Future Research Studies**

Physicians and other researchers at KU Medical Center (KUMC) conduct research to make new discoveries and promote the health of our patients. **We are asking for your permission to contact you if there is a research study for which you, your child or the person for whom you are making decisions might qualify.** Only authorized researchers with approved studies may request a list of patients willing to be contacted.

The University of Kansas Physicians, KU Hospital and KU HealthPartners will allow authorized researchers to use information in your records to identify potential study participants. We will use information such as diagnosis codes, dates of medical events or procedures, current medications, age, ethnicity, gender and zip code to determine which studies might be applicable to you or the person for whom you are signing. Authorized researchers will be given only contact information (e.g., name, e-mail address, mailing address and phone number) of individuals who may qualify for a study, and they will provide you with details about the study. You are free to say yes or no to any study.

The privacy of your health information is covered by the Federal Health Insurance Portability and Accountability Act (HIPAA). While some researchers are not required to follow the HIPAA rules, if they disclose your information, there may be other laws that protect your information from improper use.

Signing this form is completely voluntary. If you do not want to be contacted about research, do not sign this form. Choosing not to sign will have no effect on the care and services you, your child or the person for whom you are signing receives at KUMC.

This form also allows you to receive information via e-mail. There are risks associated with communications via e-mail. For instance, there is a risk that e-mail communications could be intercepted or sent to unintended parties. Our current policy is to send e-mails that contain health information through a secured system. This system will require you to create a new user name and password to access your e-mail on our servers. Our policy may change in the future to allow e-mails that contain health information be sent unsecured, like regular email.

If you want all email to be sent unsecure (if the policy changes), like regular e-mail, initial here:

If you do not want to receive any communications via e-mail, initial here: _____

Signature of Patient

Print Patient Name

Date

Signature of Parent or Legal Guardian

Print Name of Parent/Guardian and
Relationship



Date

E-mail Address

Date of Birth

You will receive a copy of this signed form. This permission for contact will stay in effect indefinitely, unless you cancel it. To cancel your permission, write to Richard Barohn, MD; Director, Frontiers: The Heartland Institute for Clinical and Translational Research; University of Kansas Medical Center, Mail Stop 6011; 4350 Shawnee Mission Pkwy; Fairway, KS 66205. If you cancel your permission, we will make the change in our records for future reference. If you have any questions about being contacted about research, please call the Frontiers Office at 913-588-6290. If you take the form home for review, make a copy and mail the signed form back to the above address.

Appendix B
Recruitment Flyer

	Predictors of Initiating and Adhering to Medication for Attention-Deficit/Hyperactivity Disorder in Children	
University of Kansas Medical Center Department of Pediatrics Principal Investigator: Michael <u>Rapoff</u> , Ph.D. Investigating Physician: Stephen Lauer, Ph.D., M.D. Research Coordinator: Catrina <u>Litzenburg</u> , M.A.		
<p>As a parent of a child with ADHD, you are being invited to participate in a research study. By doing this study, researchers hope to learn more about what things are important when speaking to parents about deciding to give their child ADHD medication.</p> <p>We know that effective treatments such as stimulant medication are available to treat ADHD in children. Some parents decide not to fill a prescription for ADHD medication.</p> <p>We want to know more about how the things parents think about when deciding to give their child ADHD medication relate to filling a new prescription for ADHD medication, and to giving this medication over time.</p>		<p>If you are interested in participating, please tell the nurse or your physician before you leave. You may also contact Catrina <u>Litzenburg</u>.</p> <p style="text-align: center;">(913) 588-2042 Clouten@ku.edu</p> <p>Study participation will involve completing questionnaires and 3 brief phone interviews. These questionnaires contain various questions about how ADHD may be challenging for your child and your attitude toward ADHD medications.</p> <p>Your child's medications will not change for the purpose of this study. No additional clinic visits are required.</p>

- Declined participation
- Agreed to be contacted
 - Contact Phone Number(s):

() _____ Home Best time to contact: _____

() _____ Mobile Best time to contact: _____

Please put patient sticker here.

Nurses – Please complete the following steps:

1. Put a patient sticker in the box provided.
2. Check a box indicating whether the parent “Declined” participation or “Agreed” to have research personnel contact them by telephone. Please write any comments on the back of this form.
3. Ask parent to provide contact phone number(s) and best time to contact them.
4. Tear at perforation. Give the top portion to the family to take home.
5. Place this bottom portion in the space provided in the clinic.



Predictors of Initiating and Adhering to Medication for Attention-Deficit/Hyperactivity Disorder in Children



University of Oklahoma Health Sciences Center

Principal Investigator: Amy Cherry, Ph.D.
 Co-Investigators: Catrina Litzenburg, M.A.
 Stephen Gillaspay, Ph.D.

As a parent of a child with ADHD, you are being invited to participate in a research study. By doing this study, researchers hope to learn more about what things are important when speaking to parents about deciding to give their child ADHD medication.



We know that effective treatments such as stimulant medication are available to treat ADHD in children. Some parents decide not to fill a prescription for ADHD medication.

We want to know more about how the things parents think about when deciding to give their child ADHD medication relate to filling a new prescription for ADHD medication, and to giving this medication over time.

If you are interested in participating, please tell the nurse or your physician before you leave.

You may also contact Catrina Litzenburg.

(405) 271-8001 ext. 59510
 Catrina-Lootens@ouhsc.edu

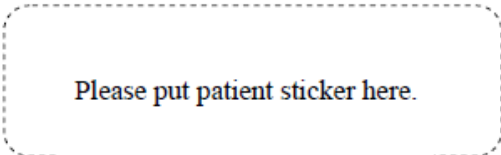
Study participation will involve completing questionnaires and 3 brief phone interviews. These questionnaires contain various questions about how ADHD may be challenging for your child and your attitude toward ADHD medications.

Your child's medications will not change for the purpose of this study. No additional clinic visits are required.

- Declined participation
- Agreed to be contacted
 - Contact Phone Number(s):

() _____ Home Best time to contact: _____

() _____ Mobile Best time to contact: _____



Please put patient sticker here.

Clinic Staff – Please complete the following steps:

1. Put a patient sticker in the box provided.
2. Check a box indicating whether the parent “Declined” participation or “Agreed” to have research personnel contact them by telephone. Please write any comments on the back of this form.
3. Ask parent to provide contact phone number(s) and best time to contact them.
4. Tear at perforation. Give the top portion to the family to take home.

Place this bottom portion in the space provided in the clinic.

The University of Oklahoma is an Equal Opportunity Institution
 IRB 4059



IRB NUMBER: 4059
 IRB APPROVAL DATE: 04/09/2014

Appendix C

Recruitment Letter

**Predictors of Initiating and Adhering to Medication for
Attention-Deficit/Hyperactivity Disorder in Children**

As a parent of a child between six and twelve years of age with attention-deficit/hyperactivity disorder (ADHD), you are being invited to participate in a study on parents' attitudes toward ADHD medication. We know some of the things parents say they think about when deciding to give their child ADHD medication. We want to know more about how these things relate to filling a new prescription for ADHD medication and to giving this medication over time.

Study activities will include completion of brief questionnaires and three telephone interviews. Your child's medications will not change for the purpose of this study. You will NOT need to have any extra visits to the clinic.

Your participation in this study is voluntary. Not participating will have no effect upon the medical care or treatment your child receives now or in the future at the University of Kansas Medical Center or at Pediatric and Adolescent Medicine.

If you are interested in participating in this study, please contact Catrina Litzenburg at (913) 588-2042 and leave your name and phone number. You can also email Catrina at email address cloutens@kumc.edu. Study staff will respond with more information.

If you would prefer to mail in this form, please fill out the below fields:

Best Contact Phone Number: _____

Best Time to be reached: _____

Mail to: Mail Stop 4004
Behavioral Pediatrics Division
The University of Kansas Medical Center
3903 Rainbow Boulevard
Kansas City, KS 66103-9906

Appendix D

Letter to Healthcare Provider

[Healthcare Provider Name]

The parent/guardian of one of your patients recently consented to participate in the *Predictors of Initiating and Adhering to Medication for Attention-Deficit/Hyperactivity Disorder in Children* study being conducted in partnership with the University of Oklahoma Health Sciences Center and the University of Kansas Medical Center. I have included a copy of the authorization for the release of confidential information form signed by [parent/guardian name], [child's name]'s [relationship to child]. During the informed consent process we explained to [parent/guardian name], that we would be contacting you to confirm the child's ADHD diagnosis and current medications. If you could either complete and return the information below, or send us this information in whatever format you currently have, we would greatly appreciate it. Please feel free to contact me with any questions you may have. Thank you very much.

The child listed below does does not receive care at our facility.

Patient Name: _____

Date of Birth: _____

He/she does does not have a diagnosis of ADHD.

Please list all of the child's currently prescribed medications.

Medication Name	Dosage	Frequency

Comments: _____

Please do not hesitate to contact us with any questions or concerns. Thank you very much for your time and help.

Catrina C. Litzenburg, M.A.
OUHSC: Psychology Trainee
KUMC: Research Coordinator
Phone: (405)271-4407
Fax: (405)271-8709
Cloutens@kumc.edu

Appendix E

Frontiers Research Participant Registry Phone Script

“Hello. May I speak to the parent or guardian of [name]? My name is Catrina Litzenburg. I am contacting you because at some point you signed your child up for the Frontiers Research Participant Registry through a clinic at the University of Kansas Medical Center. This means that you agreed to be contacted if there are any studies for which your child might qualify. Our research team includes Drs. Stephen Lauer and Michael Rapoff from the Department of Pediatrics at KUMC. You are free to say “no” if you do not want your child to participate in the study. May I tell you about a study that we are conducting on initiating and adhering to medication for attention-deficit/hyperactivity disorder in children?”

If no: “I appreciate your time. Were you aware of the registry before my calling? Had you been contacted for any other registry projects?”

If yes: “By doing this study, researchers hope to learn more about what things are important when speaking to parents about deciding to give their child ADHD medication. If you decide to participate in this study, your participation will last approximately three months. Participation does not require any additional clinic visits and can take place entirely over the phone, Internet, and mail. The questionnaires and telephone interviews will take approximately 15 minutes each time to complete. Your child’s medications will not change for the purpose of this study, but each prescription will be recorded at the pharmacy. Do you think you might be interested in participating?”

If no: “I appreciate your time. Were you aware of the registry before my calling? Had you been contacted for any other registry projects?”

If yes: “Do you mind if I ask you a few quick questions to see if you are eligible to participate in this study?”

Is your child 6 to 12 years old?

Do they have a diagnosis of Pervasive Developmental Disorder or Mental Retardation?

Has your child ever taken a medication to treat ADHD?

Do you anticipate pursuing a medication to treat ADHD? Or are you currently considering medication options for ADHD?

Does your child currently take any daily medications? If so, what are those?”

“I will go ahead and mail you some additional information about the study. Is this your correct mailing address? ... After you receive the information in the mail we will schedule a time to complete the informed consent process over the telephone. When is generally a convenient time to call you?”

Appendix F
Pharmacy Study Letter

[Pharmacy Name]

The parent/guardian of one of your patients recently consented to participate in the *Predictors of Initiating and Adhering to Medication for Attention-Deficit/Hyperactivity Disorder in Children* study being conducted in partnership with the University of Oklahoma Health Sciences Center and the University of Kansas Medical Center. I have included a copy of the authorization for the release of confidential information form signed by [parent/guardian name], [child's name]'s [relationship to child]. During the informed consent process we explained to [parent/guardian name], that we would be contacting the pharmacy to obtain the child's prescription history. We need the name, number of pills dispensed, and date filled for each prescription for [child's name], [Date of Birth], from [Date – 6 months prior] to present. If you could either complete and return the information below, or send us this information in whatever format you currently have, we would greatly appreciate it. Please feel free to contact me with any questions you may have. Thank you very much for your time.

The prescriptions included below have been filled for [Child's name] in the past 6 months:

Name of Medication	Dose	Frequency	Number of pills dispensed	Date Prescription Filled

Catrina C. Litzenburg, M.A.
OUHSC: Psychology Trainee
KUMC: Research Coordinator
Phone: (405)271-4407
Fax: (405)271-8709
Catrina-Litzenburg@ouhsc.edu

Appendix G

Demographic Questionnaire

How are you related to the child who will be participating in this study?

- Mother
- Grandparent
- Father
- Other (please describe) _____

What is your current marital status?

- Single
- Divorced
- Married
- Not married, live with partner
- Separated

Please describe the occupation of both parents.

Mother: _____

Father: _____

Annual Household Income:

- Less than \$10,000
- \$10,001-\$30,000
- \$30,001-\$50,000
- \$50,001-\$70,000
- \$70,001-\$100,000
- More than \$100,001

What type of health insurance does the child have?

- Medicaid
- Private

Gender of the child:

- Male
- Female

Child's current grade in school: _____

Please identify the child's ethnicity.

- Hispanic or Latino
- Not Hispanic or Latino

Please identify the child's race. Select all that apply.

- American Indian or Alaska Native
- Black or African American
- Native Hawaiian or Other Pacific Islander
- Asian
- White

What is the highest grade level completed by the child's mother?

- less than 7th grade
- partial high school
- some college or specialized training
- graduate/professional training
- junior high school
- high school graduate
- college graduate

What is the highest grade level completed by the child's father?

- | | |
|---|---|
| <input type="checkbox"/> less than 7 th grade | <input type="checkbox"/> junior high school |
| <input type="checkbox"/> partial high school | <input type="checkbox"/> high school graduate |
| <input type="checkbox"/> some college or specialized training | <input type="checkbox"/> college graduate |
| <input type="checkbox"/> graduate/professional training | |

Please list the name of the professional who diagnosed the child with ADHD.

Is this person a psychologist or a medical doctor?

- psychologist (Ph.D.) medical doctor (M.D.)

Please list any mental health diagnoses (other than ADHD) the child has.

Is your child currently being seen by a mental health specialist to treat ADHD?

- Yes No

What other ADHD treatments have you tried for your child? Please indicate if you are currently using the treatments.

- | Past | Current | | Past | Current | |
|--------------------------|--------------------------|--|--------------------------|--------------------------|------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Behavioral parent training | <input type="checkbox"/> | <input type="checkbox"/> | Social skills training |
| <input type="checkbox"/> | <input type="checkbox"/> | Behavioral classroom management | <input type="checkbox"/> | <input type="checkbox"/> | Dietary changes |
| <input type="checkbox"/> | <input type="checkbox"/> | Anti-motion sickness medication | <input type="checkbox"/> | <input type="checkbox"/> | Play therapy |
| <input type="checkbox"/> | <input type="checkbox"/> | Individual child therapy | <input type="checkbox"/> | <input type="checkbox"/> | Cognitive therapy |
| <input type="checkbox"/> | <input type="checkbox"/> | Problem-solving communication training | <input type="checkbox"/> | <input type="checkbox"/> | Exercise |
| <input type="checkbox"/> | <input type="checkbox"/> | Optometric visual training | <input type="checkbox"/> | <input type="checkbox"/> | Sensory integration |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment for lead toxicity | <input type="checkbox"/> | <input type="checkbox"/> | Nutrition supplements |
| <input type="checkbox"/> | <input type="checkbox"/> | Interactive metronome training | <input type="checkbox"/> | <input type="checkbox"/> | Biofeedback |
| <input type="checkbox"/> | <input type="checkbox"/> | Candidas yeast therapy | <input type="checkbox"/> | <input type="checkbox"/> | Applied kinesiology |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment for thyroid dysfunction | <input type="checkbox"/> | <input type="checkbox"/> | Other |

(please describe): _____

Do you have another child who has taken ADHD medication?

Yes No

How many other children (not including this one) do you have who have taken ADHD medication before? _____

Do you have a family member, friend, or acquaintance that has a child who has taken ADHD medication? Yes No

Did your child's doctor say you could skip ADHD medication on the weekend?

Yes No

Do you intend to skip doses of ADHD medication on purpose?

Yes No

Please explain: _____

Please select the medication(s) the child is currently prescribed for ADHD. Please select how often (frequency) the child is prescribed each medication.

Trade Name (Generic Name)	Frequency per day		
<input type="checkbox"/> Adderall (amphetamine)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Adderall XR (amphetamine – extended release)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Concerta (methylphenidate – long acting)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Daytrana (methylphenidate patch)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Desoxyn (methamphetamine hydrochloride)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Dexedrine (dextroamphetamine)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Dextrostat (dextroamphetamine)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Focalin (dexmethylphenidate)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Focalin XR (dexmethylphenidate – extended release)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Intuniv (guanfacine)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Metadate ER (methylphenidate – extended release)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Metadate CD (methylphenidate – extended release)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Methylin (methylphenidate – oral solution and chewable tablets)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Ritalin (methylphenidate)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Ritalin SR (methylphenidate – extended release)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Ritalin LA (methylphenidate – long acting)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Strattera (atomoxetine)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Vyvanse (lisdexamfetamine dimesylate)	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times
<input type="checkbox"/> Other _____	<input type="checkbox"/> Once	<input type="checkbox"/> Twice	<input type="checkbox"/> Three times

Appendix H

Protected Health Information Sheet

Child's date of birth: _____

Mother's date of birth: _____

Father's date of birth: _____

Current mailing address: _____

Current cell phone number: _____

Current home phone number: _____

Best time to reach you by phone: _____

What is the name of your child's school? _____

What is the name of your child's school district? _____

Date of child's ADHD diagnosis: _____

Date your child began treatment for ADHD: _____

What is the name of the pharmacy where you have your child's medications filled?

What is the address of the pharmacy where you have your child's medications filled?

What is the name of the healthcare professional that provides medical care for your child (e.g., PCP)?

What is the phone number of this healthcare professional?

Appendix I
Medication Recommendation

Please mark the line below with a vertical stroke to show how much you agree with the statement. A mark at the extreme left would show that you completely agree with the statement. A mark at the extreme right would show that you completely disagree with the statement. A mark near the center would show that you neither disagree nor agree with the statement.

“My child’s doctor was too hasty in his/her recommendation of ADHD medication.”

Agree _____ Disagree