



Published in final edited form as:

*Acad Pediatr.* 2018 April ; 18(3): 273–280. doi:10.1016/j.acap.2017.09.005.

## Reasons Why Children and Adolescents with ADHD Stop and Restart Taking Medicine

William B. Brinkman, MD, MEd, MSc<sup>1</sup>, John O. Simon, MA<sup>1</sup>, and Jeffery N. Epstein, PhD<sup>1</sup>

<sup>1</sup>Department of Pediatrics, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, Cincinnati, OH 45229-3039

### Abstract

**Objective**—To describe the prevalence of reasons why children and adolescents stop and restart attention-deficit/hyperactivity disorder (ADHD) medicine and whether functional impairment is present after stopping medicine.

**Methods**—We used the prospective longitudinal cohort from the Multimodal Treatment of Study of Children with ADHD. At the 12 year follow-up when participants were a mean of 21.1 years old, 372 participants (76% male, 64% Caucasian) reported ever taking ADHD medicine. Participants reported the age when they last stopped and/or restarted ADHD medicine and also endorsed reasons for stopping and restarting.

**Results**—Seventy-seven percent (286/372) reported stopping medicine for a month or longer at some time during childhood or adolescence. Participants were a mean of 13.3 years old when they last stopped medicine. The most commonly endorsed reasons for stopping medication related to 1) medicine not needed/helping, 2) side effects, 3) logistical barriers of getting/taking medication, and 4) social concerns/stigma. Seventeen percent (64/372) reported restarting medicine after stopping for a month or longer. Commonly endorsed reasons for restarting related to 1) medicine needed/helped, 2) resolution of logistical barriers to getting/taking. For both stopping and restarting, the proportion endorsing some reasons differed by age range, with the overall pattern suggesting that parental involvement in decisions decreased with age. Nearly all participants had impairment at the assessment after stopping regardless of whether medication was resumed.

**Conclusions**—Different reasons for stopping and/or restarting medicine are relevant at different times for different teens. Tailored strategies may help engage adolescents as full partners in their treatment plan.

### Keywords

ADHD; Adherence; Decision-making; Child; Adolescent [3–5]

---

Corresponding author: Name: William B. Brinkman, Mailing address: 3333 Burnet Avenue, mail location 7035, Cincinnati, OH 45229-3039, bill.brinkman@cchmc.org, Phone and fax numbers: 513-636-2576 (phone), 513-636-4402 (fax).

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Dr. Brinkman and Mr. Simon report no biomedical financial interests or potential conflicts of interest.

## Introduction

Attention-deficit/hyperactivity disorder (ADHD) is the most common mental health condition of childhood<sup>1</sup> affecting 6.4 million children aged 4–17 years in the United States.<sup>2</sup> Children with ADHD experience impairments across a wide range of areas of functioning including academics, social relationships, and family functioning.<sup>3</sup> Fortunately, effective treatments for ADHD exist. Stimulant medications, either alone or in combination with behavior therapy, effectively reduce ADHD symptoms and some areas of impairment<sup>4, 5</sup> and are recommended as a first-line treatment in clinical practice guidelines.<sup>6</sup>

Medication use is quite common among children with ADHD, but medication continuity is poor as children often stop and re-start medication in the first year of treatment.<sup>7, 8</sup> Moreover, use declines dramatically after age eleven<sup>2</sup> even though adolescents continue to demonstrate symptoms and functional impairment.<sup>9</sup> Teens who continue to take medicine take their medications inconsistently (i.e., only 50% of days covered with medicine; Molina et al. 2009).<sup>10</sup> Unfortunately, at the same time medication continuity declines, the outcomes of ADHD become increasingly consequential. For example, adolescents with ADHD, compared to their non-ADHD peers, are more likely to drop out of school, use tobacco and illicit drugs, interact with the juvenile justice system, be treated for sexually transmitted infections, have motor vehicle accidents, and experience teenage pregnancies.<sup>10–12</sup> Given that medication has large effects on adolescent performance across a variety of domains (e.g. academic tasks, social skills, driving performance, etc.),<sup>5, 13–15</sup> poor medication continuity represents a significant public health problem.

Qualitative research has elucidated some reasons why children and adolescents with ADHD stop taking medicine.<sup>16–22</sup> For example, some don't believe that medication helps. Others don't like the way medication makes them feel. However, there are no published reports which quantify these phenomena in large cohorts with ADHD. We sought to describe the prevalence of reasons why children and adolescents stop and restart ADHD medicine, whether functional impairment is present after stopping medicine, and whether parent and adolescent ratings of impairment differ. This information is needed so strategies can be developed to promote medication continuity.

## Methods

### Design and Participants

We used publically available data from the Multimodal Treatment Study of Children with ADHD (MTA) prospective longitudinal cohort. Participants were originally recruited at 6 sites in the United States and one site in Canada. Following a 14-month randomized clinical trial with 579 participants aged 7.0 – 9.9 years, the study continued as a naturalistic longitudinal cohort with follow-up assessments at 2, 3, 6, 8, 10, and 12 years after enrollment. The study retained 427 of 579 (73.7%) participants at the 12 year follow up assessment point when a survey was collected to assess the reasons behind stopping and/or restarting ADHD medication.<sup>23</sup> Previous analyses of adult outcomes indicated MTA participants with and without complete data were not significantly different on most baseline demographic variables and 'missing at random' criteria were met.<sup>9</sup> Of the 427, 372 reported

using ADHD medicine during their lifetime. The current study includes 296 participants who reported stopping (n=286) and/or restarting (n=64) ADHD medicine during childhood or adolescence (i.e. up to age 17 years). Participants were a mean (standard deviation [SD]) age of 21.0 (1.1) years at the 12 year follow-up. Seventy-six percent were male, 64% were Caucasian, 19% were African American, 6% were Hispanic, and 9% reported more than one racial/ethnic category.

## Measures

The MTA Cooperative Group developed the “ADHD Med Reasons” questionnaire. Items were drafted and iteratively refined based on expert review. The questionnaire asked participants to report the age when they last stopped taking medicine for a month or longer and endorse how true each reason listed was for them in describing why they stopped medication at that time using a 6-point scale with anchors of 1 = really true and 6 = not true at all. We dichotomized the scale (i.e. response 1–3 = true, response 4–6 = not true) and calculated the proportion endorsing each reason as true. Participants could endorse multiple reasons (see Table 1 for list of reasons). Participants were asked to complete similar questions related to the last time they restarted ADHD medicine after stopping for a month or longer (see Table 2 for list of reasons). The psychometric properties of the “ADHD Med Reasons” questionnaire have not been established.

The MTA study collected measures of functional impairment, with parents completing a rating at every follow-up visit and participants providing a self-rating at visits during adolescence and emerging adulthood. At the 2, 3, and 6 year assessment time points, parents completed the Columbia Impairment Rating Scale (CIS).<sup>24</sup> At the 8, 10, and 12 year assessment time points, parents and participants completed the Impairment Rating Scale (IRS) which has parent (PIRS) and adult (AIRS) versions.<sup>25</sup> The CIS assesses impairment in behavioral, emotional, interpersonal, and task-related functioning. Behavioral functioning includes problems with behavior at home and school; emotional impairment involves feeling nervous or sad; interpersonal impairment taps problems in relationships with peers, siblings, parents, and other adults; and task-related functioning includes problems with schoolwork and involvement in leisure activities. Parents reported how much of a problem each of these areas of impairment were for their child on 13 items using a 7-point scale (“no problem” to “extreme problem”). The CIS has shown high internal consistency, excellent test-retest reliability, and good validity when correlated with a clinician's score on the Children's Global Assessment Scale.<sup>24</sup> The PIRS and AIRS contain seven domains (relationship with peers, relationship with siblings, relationship with parents, academic progress, self-esteem, influence on family functioning, and overall impairment). The instructions ask the rater to assess the severity of the participant's problem in each domain using a 5 point scale (“no problem” to “a very bad problem”). The PIRS and AIRS have strong concurrent, predictive, convergent, and discriminant validity.<sup>25</sup>

Among participants who reported stopping medicine, we examined impairments at the MTA assessment follow-up visit that followed the reported medication stoppage. To understand whether participants remained off medicine at this assessment point, we examined parent and participant reports of medication use. For the 2, 3, 6, 8, and 10 year assessment time

points, medication use was based on parent responses to the Services for Children & Adolescents –Interview. This is a reliable measure of ADHD service use, including medication use.<sup>26</sup> For the 12 year assessment time point, medication use was based on participant responses to a single question: “Are you currently taking ADHD medication?” with response options of “no”, “yes, some of the time”, and “yes, most of the time”. We categorized participants as having “no” medication versus any medication at that assessment point and used the CIS, IRS, and PIRS to measure the participant’s level of functional impairment.

## Analysis

We calculated descriptive statistics to summarize participant demographic characteristics, the prevalence reasons for stopping and restarting ADHD medicine during childhood and adolescence, the number of reasons endorsed per participant, and the number of years since the stopping/restarting incident on which they are reporting. We used analysis of variance to test whether the age of last stopping or restarting varied by the participant’s original treatment group membership during the 14 month randomized controlled trial (i.e. community control group, medication management group, behavior therapy group, or combined treatment group). We used Chi-squares and Fisher’s exact to test whether the proportion endorsing each reason was different among those stopping/re-starting in childhood (5–12 years) vs. adolescence (13–17 years). To examine functional impairment among participants who reported stopping medicine on the “ADHD Medication Reasons” questionnaire, we analyzed impairment ratings obtained at the follow-up assessment time point subsequent to the last reported stop. Because participants reported stopping medicine at a variety of ages, this analysis drew from data multiple assessment time points. We calculated the proportion of participants with impairment on each impairment item and overall considering all impairment items. We considered any response other than “No problem” as indicative of impairment because the CIS, PIRS, and AIRS all included this response anchor. We used t- and Fisher’s exact tests to compare participants with and without medication resumption after the reported stop on the mean number of impairments and the proportion with impairment on any item, respectively. For the 53 subjects who remained off medicine and had both parent and participant ratings of impairment, we used the Wilcoxon signed rank test to determine whether ratings differed by rater (self vs. parent).

## Results

Seventy-seven percent of participants with a history of taking ADHD medicine (286/372) reported last stopping medicine for a month or longer during childhood (ages 5–12; n=115) or adolescence (ages 13–18; n=171). Participants were a mean (SD) of 13.3 (3.0) years when they last stopped medicine. Seventeen percent of participants (64/372) reported last restarting medicine after stopping for a month or longer during childhood (n=15) or adolescence (n=49). Participants were a mean (SD) of 14.5 (3.4) years when they last restarted medicine. MTA original treatment group membership (i.e. community control group, medication management group, behavior therapy group, or combined treatment group) did not impact the age at last stop ( $F(3,292) = 0.24, p=0.87$ ) or restart ( $F(3,69) = 0.76, p=0.52$ ).

Among participants who reported stopping medicine during childhood or adolescence, the mean (SD) number of reasons endorsed was 7.1 (3.3). Commonly endorsed reasons for stopping related to 1) medicine was not needed or helping, 2) side effects, 3) logistical barriers to getting or taking medicine, 4) social concerns or stigma, and 5) other reasons (i.e. tired of taking it, summer, parents decided to stop) (Table 1). A majority of participants endorsed reasons related to not feeling like medicine was needed or helping. One-third to one-half of participants endorsed reasons related to side effects. Twenty-seven percent of participants endorsed forgetting to take medicine, but reasons related to logistical challenges of obtaining medicine (e.g., cost, getting prescriptions) were less common. Less than twenty percent of participants endorsed social concerns or stigma as reasons for stopping medicine. A large majority (68.6%) of participants endorsed, “I was tired of taking it.” The mean (SD) number of years since the stopping incident on which they were reporting was 7.7 (3.1).

Among participants who reported re-starting medicine during childhood or adolescence, the mean (SD) number of reasons endorsed was 5.2 (2.3). Commonly endorsed reasons for restarting related to 1) medicine was needed/helped, 2) resolution of logistical barriers to getting/taking, and 3) other reasons (e.g. planned to re-start when school began, parents decided to re-start it, allowed to decide when to take it) (Table 2). Over 80% of participants cited reasons related to noticing benefit from medication at school or work as a reason for restarting. Nearly half of participants endorsed realizing that they needed medicine after they had stopped. Half of participants endorsed restarting medicine after stopping for the summer or because they were allowed to take medicine selectively. The mean (SD) number of years since the restarting incident on which they were reporting was 6.3 (3.5).

Significant age-related differences were present for 6 of the 20 reasons for stopping (Table 1) and 1 of the 11 reasons for restarting (Table 2). Regarding age-related differences on reasons for stopping, five items suggest that parent influence decreased (i.e. my parents wanted to find out if I could manage without it, my parents decided to stop it) and autonomy increased (i.e. I wanted to find out if I could manage without it, I kept forgetting to take it, I was tired of taking it) as participant age increased. Stopping medicine for the summer was more common during adolescence compared to childhood (34% vs. 20%). Restarting medicine because “It stopped me from being impulsive” was more common during childhood compared to adolescence (60% vs. 31%).

Among the 286 participants who reported stopping medicine, 166 remained off medicine at the next follow-up assessment point, 95 resumed medicine, and 25 had missing data related to their medication status or impairment (Table 3). Nearly all participants who stopped medication (97.5% (162/166) had at least one impairment at the MTA follow-up assessment time point subsequent to the last reported stop. However, there was no difference in the proportion of participants impaired between those that stopped and those participants who resumed medication (98.8%,  $p=1.0$ ). Moreover, those who stopped and those who resumed medication did not differ on the mean (SD) number of impairments (7.1 [3.4] vs. 7.9 [2.8],  $p=0.41$ ). For participants who remained off medication, impairment was common across multiple domains of functioning and parents consistently provided higher ratings of impairment than did participants (Table 4). Problems with schoolwork were the most commonly reported impairment.

## Discussion

Participants were a mean of 13.3 years old when they last stopped medicine. Commonly endorsed reasons for stopping related to 1) medicine not being needed or helping, 2) side effects, 3) logistical barriers to getting or taking medicine, and 4) social concerns or stigma. Participants were a mean of 14.5 years when they last restarted medicine. Commonly endorsed reasons for restarting related to 1) medicine needed/helped, 2) resolution of logistical barriers to getting/taking. For both stopping and restarting, the proportion endorsing some reasons differed by age range, with the overall pattern suggesting that parental involvement decreased and autonomy increased as child age increased. Nearly all participants had impairment at the assessment after stopping regardless of whether medication was resumed.

Qualitative research conducted by our team<sup>16, 17</sup> and others<sup>18–22</sup> previously elucidated reasons why children and adolescents stop and/or restart taking medicine. However, our analysis of the relative prevalence of these reasons in a large prospective longitudinal cohort shines a new light on past reports. For example, past qualitative research have prominently featured teen reports of negative feelings toward medication due to the experience of side effects. However, participants in our analysis more commonly endorsed lack of need for and/or benefit from medication, rather than side effects, as a reason for stopping and the converse for re-starting medicine. This seems to suggest that many teens are willing to tolerate side effects to some extent as long as they perceive adequate benefit from medication. Beliefs about the necessity and helpfulness of medicine have been shown to impact adherence across a range of medical conditions,<sup>27, 28</sup> though the focus on benefit in school performance is unique to ADHD.

Forgetting to take medicine was endorsed by 26% of participants as a reason for stopping for 30 days or more. It is possible that forgetting is much more common, but medication is resumed within 30 days. It is noteworthy that the rate of reporting forgetting as a reason nearly doubled from childhood (16.5%) to adolescence (31.6%). This likely relates to parents playing a greater role providing reminders and directly observing medication taking during childhood. Text message reminders and other interventions to embed pill taking in a teen's daily routine with a level of parent supervision commensurate to the teen's developmental and organizational capacities hold promise to improve medication continuity. Other logistical barriers weren't extremely prevalent as less than 10% of participants stopped taking medicine for 30 days or more due to difficulty obtaining a prescription from a physician or getting the prescription filled due to out-of-pocket cost or lack of insurance coverage. However, these issues were likely critical to those who experienced them. Indeed, the heterogeneous nature of teen reasons for stopping medicine makes efforts to support medication continuity challenging. Different reasons are relevant at different times for different teens. Tailored interventions are needed to meet the needs of each individual.

The near universal presence of impairment after stopping medicine raises the question of whether participants made a well informed decision. Resumption of medication use after a stop had no apparent impact on measures of impairment during adolescence which runs counter to literature suggesting certain domains of adolescent functioning (e.g. academic

tasks, social skills, driving, etc.) improve with medication use.<sup>5, 13–15</sup> It is possible that adolescent use of medicine was too inconsistent to impact impairment or that our measure of impairment wasn't sensitive enough to detect differences in these areas. It is also possible that, on average, medication treatment doesn't significantly impact parent-reported impairments.<sup>29</sup> Among those that restarted medicine, it is noteworthy that 41% recognized the need for medicine only after stopping. This finding is consistent with our past qualitative research which found that teens and parents developed insight into their functional impairments by contrasting time spent on and off medication.<sup>16, 17</sup> Structured trials on/off medication with objective measures of outcome have been proposed to inform decisions about the continued benefit from and/or need for ADHD medicine.<sup>30</sup> This may be especially important for teenagers as ADHD medication use plummets during adolescence.<sup>2</sup> Indeed, approaches to enable teens with ADHD to more objectively assess benefit/need is appealing for many reasons. First, objective measures of outcome may help address the unrealistically high self-views of performance (i.e. positive illusory bias) that have been observed among teens with ADHD.<sup>31</sup> This phenomena likely explains the discrepancy between parent- and self-ratings of impairment evident in our study. Second, measuring proximal outcomes that matter to teens and parents might detect an early signal of the continued need for and benefit from medicine, potentially averting sentinel events (e.g. class failure, auto accident). Third, structured trials on/off medicine could provide a concrete way for teens and parents to work together. Parents may be afraid to give their teen a say in the decision because they believe medicine works and worry that teen goals are short sighted.<sup>16, 17</sup> This can lead to teens who rebel by conducting covert trials off medicine that lack structure and formal measurement. When parents discover that their teen has stopped taking medicine because they experience a negative outcome (e.g. grades declining), this undermines trust, precipitates family conflict, and makes collaboration even more challenging.<sup>17</sup>

For both stopping and restarting, the proportion endorsing some reasons differed by age range, with the overall pattern suggesting that parental involvement decreased and autonomy increased as child age increased. The American Academy of Pediatrics recommends that pediatricians gradually empower children with ADHD to be full partners in their treatment plan by adolescence.<sup>30</sup> Similar to other chronic health conditions, child involvement in ADHD care often starts as a reporter of symptoms and side effects. As children mature, their role in self-care and decision making increases.<sup>17</sup> Collaborative decision making between parents and children is a part of normative development that precedes full decision-making autonomy.<sup>32</sup> Children often seek their parents' input into health-related decisions and such decisions continue to be influenced by parents into young adulthood.<sup>33, 34</sup> There are a variety of ways in which children and younger adolescents can be involved in decision making without necessarily having final decision-making authority.<sup>35</sup> Children can be given information about the decision or express an opinion or concerns about the decision to be made.<sup>36</sup> Some have hypothesized that such involvement teaches children what factors to consider when making decisions, the potential outcomes of different decisions, and the communication skills to influence decisions.<sup>35</sup> In addition to these potential effects on children's decision-making skills, their involvement may positively impact self-efficacy, ability to cope with illness, satisfaction with medical care, adherence to treatment, and, ultimately, the transition to adult health care.<sup>32, 35, 37, 38</sup> In addition, open communication

between adolescents and parents is strongly associated with less family conflict.<sup>32</sup> Ultimately, each family must strike a balance between parents providing supervision and support for managing ADHD and the adolescent taking on more responsibility in light of their increasing capacity and maturity.<sup>39</sup>

This study has limitations. There is a risk for recall bias in participant retrospective self-reports. This risk is especially relevant given that participant reports about the reasons for stopping medicine were made an average of 7.7 years after stopping medication. For example, two participants reported that “It helped me concentrate when I drove” as a reason for restarting decisions that were made during childhood when driving wasn’t a relevant factor. Another limitation is that the “ADHD Med Reasons” questionnaire was developed through an iterative process whereby the MTA Cooperative Group drew upon their research and clinical expertise related to pharmacotherapy for adolescents with ADHD. The measure has good face validity, but the psychometric properties (e.g. test-retest reliability) of this instrument are unknown. This study was also limited by a lack of information about whether medication was taken as prescribed. This is noteworthy because past reports have documented that adolescents often misuse (i.e. take too much, etc.) and/or divert (i.e. give away, sell, trade, etc.) ADHD medicines.<sup>40</sup>

## Conclusions

Stopping and/or re-starting medicine is common among children and adolescents with ADHD. Adolescents exert more control over choices, but the vast majority remain impaired. Given the poor outcomes experienced by many adolescents with ADHD, additional support may be needed during the transition from family- to self-management of ADHD. Physician supervised trials on/off medicine may help curious adolescents more objectively assess performance. Among those who benefit from medication, tailored approaches may be needed to support continuity of treatment.

## Acknowledgments

Drs. Brinkman and Epstein were supported by grants K23MH083027 and K24MH064478 from the National Institute of Mental Health (NIMH), respectively. The funders played no role in study design or conduct; data collection, management, analysis, or interpretation; preparation, review, or approval of the manuscript; or decision to submit the manuscript for publication. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Data used in the preparation of this manuscript was obtained and analyzed from the controlled access datasets distributed from the NIMH-supported National Database for Clinical Trials (NDCT). NDCT is a collaborative informatics system created by NIMH to provide a national resource to support and accelerate discovery related to clinical trial research in mental health.

MTA Study U01MH050453

Dataset identifier: #2155

This manuscript reflects the views of the authors and may not reflect the opinions or views of the NIMH or of the Submitters submitting original data to NDCT.

Dr. Epstein has received research funding and consulting fees from Akili Interactive Labs. He and his institution own the intellectual property and licensing rights for an internet-based software to help primary care pediatricians deliver high quality ADHD care.



## References

1. Perou R, Bitsko RH, Blumberg SJ, et al. Mental health surveillance among children--United States, 2005–2011. *MMWR Surveill Summ*. 2013; 62(Suppl 2):1–35.
2. Visser SN, Danielson ML, Bitsko RH, et al. Trends in the parent-report of health care provider-diagnosed and medicated attention-deficit/hyperactivity disorder: United States, 2003–2011. *J Am Acad Child Adolesc Psychiatry*. 2014; 53:34–46. e32. [PubMed: 24342384]
3. Wehmeier PM, Schacht A, Barkley RA. Social and emotional impairment in children and adolescents with ADHD and the impact on quality of life. *J Adolesc Health*. 2010; 46:209–217. [PubMed: 20159496]
4. The MTA Cooperative Group. A 14-month randomized clinical trial of treatment strategies for attention-deficit/hyperactivity disorder. Multimodal Treatment Study of Children with ADHD. *Arch Gen Psychiatry*. 1999; 56:1073–1086. [PubMed: 10591283]
5. Chan E, Fogler JM, Hammerness PG. Treatment of Attention-Deficit/Hyperactivity Disorder in Adolescents: A Systematic Review. *JAMA*. 2016; 315:1997–2008. [PubMed: 27163988]
6. Wolraich M, Brown L, Brown RT, et al. ADHD: clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics*. 2011; 128:1007–1022. [PubMed: 22003063]
7. Brinkman WB, Baum R, Kelleher KJ, et al. Relationship Between Attention-Deficit/Hyperactivity Disorder Care and Medication Continuity. *J Am Acad Child Adolesc Psychiatry*. 2016; 55:289–294. [PubMed: 27015719]
8. Marcus SC, Wan GJ, Kemner JE, Olfson M. Continuity of methylphenidate treatment for attention-deficit/hyperactivity disorder. *Arch Pediatr Adolesc Med*. 2005; 159:572–578. [PubMed: 15939858]
9. Howard AL, Strickland NJ, Murray DW, et al. Progression of impairment in adolescents with attention-deficit/hyperactivity disorder through the transition out of high school: Contributions of parent involvement and college attendance. *J Abnorm Psychol*. 2016; 125:233–247. [PubMed: 26854508]
10. Molina BS, Hinshaw SP, Swanson JM, et al. The MTA at 8 years: prospective follow-up of children treated for combined-type ADHD in a multisite study. *J Am Acad Child Adolesc Psychiatry*. 2009; 48:484–500. [PubMed: 19318991]
11. Barkley RA, Fischer M, Smallish L, Fletcher K. Young adult outcome of hyperactive children: adaptive functioning in major life activities. *J Am Acad Child Adolesc Psychiatry*. 2006; 45:192–202. [PubMed: 16429090]
12. Bussing R, Mason DM, Bell L, Porter P, Garvan C. Adolescent Outcomes of Childhood Attention-Deficit/Hyperactivity Disorder in a Diverse Community Sample. *J Am Acad Child Adolesc Psychiatry*. 2010; 49:595–605. [PubMed: 20494269]
13. Evans SW, Pelham WE, Smith BH, et al. Dose-response effects of methylphenidate on ecologically valid measures of academic performance and classroom behavior in adolescents with ADHD. *Exp Clin Psychopharmacol*. 2001; 9:163–175. [PubMed: 11518092]
14. Smith BH, Pelham WE, Evans S, et al. Dosage effects of methylphenidate on the social behavior of adolescents diagnosed with attention-deficit hyperactivity disorder. *Exp Clin Psychopharmacol*. 1998; 6:187–204. [PubMed: 9608351]
15. Cox DJ, Merkel RL, Moore M, Thorndike F, Muller C, Kovatchev B. Relative benefits of stimulant therapy with OROS methylphenidate versus mixed amphetamine salts extended release in improving the driving performance of adolescent drivers with attention-deficit/ hyperactivity disorder. *Pediatrics*. 2006; 118:e704–710. [PubMed: 16950962]
16. Brinkman WB, Sherman SN, Zmitrovich AR, et al. Parental Angst Making and Revisiting Decisions About Treatment of ADHD. *Pediatrics*. 2009; 124:580–589. [PubMed: 19651580]
17. Brinkman WB, Sherman SN, Zmitrovich AR, et al. In their own words: adolescent views on ADHD and their evolving role managing medication. *Acad Pediatr*. 2012; 12:53–61. [PubMed: 22133501]
18. Charach A, Yeung E, Volpe T, Goodale T, Dosreis S. Exploring stimulant treatment in ADHD: narratives of young adolescents and their parents. *BMC Psychiatry*. 2014; 14:110. [PubMed: 24725829]

19. Leslie LK, Plemmons D, Monn AR, Palinkas LA. Investigating ADHD treatment trajectories: listening to families' stories about medication use. *J Dev Behav Pediatr.* 2007; 28:179–188. [PubMed: 17565284]
20. Hansen DL, Hansen EH. Caught in a Balancing Act: Parents' Dilemmas Regarding Their ADHD Child's Treatment With Stimulant Medication. *Qual Health Res.* 2006; 16:1267–1285. [PubMed: 17038757]
21. Knipp DK. Teens' Perceptions about Attention Deficit/Hyperactivity Disorder and Medications. *The Journal of School Nursing.* 2006; 22:120–125. [PubMed: 16563036]
22. Meaux JB, Hester C, Smith B, Shoptaw A. Stimulant medications: a trade-off? The lived experience of adolescents with ADHD. *J Spec Pediatr Nurs.* 2006; 11:214–226. [PubMed: 16999743]
23. Swanson JM, Arnold LE, Molina BS, et al. Young adult outcomes in the follow-up of the multimodal treatment study of attention-deficit/hyperactivity disorder: symptom persistence, source discrepancy, and height suppression. *J Child Psychol Psychiatry.* 2017
24. Bird HR, Shaffer D, Fisher P, et al. The Columbia Impairment Scale (CIS): pilot findings on a measure of global impairment for children and adolescents. *Int J Methods Psychiatr Res.* 1993; 3:167–176.
25. Fabiano GA, Pelham WE Jr, Waschbusch DA, et al. 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. *J Clin Child Adolesc Psychol.* 2006; 35:369–385. [PubMed: 16836475]
26. Eaton Hoagwood K, Jensen PS, Arnold LE, et al. Reliability of the services for children and adolescents-parent interview. *J Am Acad Child Adolesc Psychiatry.* 2004; 43:1345–1354. [PubMed: 15502593]
27. Conn KM, Halterman JS, Lynch K, Cabana MD. The impact of parents' medication beliefs on asthma management. *Pediatrics.* 2007; 120:e521–526. [PubMed: 17766496]
28. Foot H, La Caze A, Gujral G, Cottrell N. The necessity-concerns framework predicts adherence to medication in multiple illness conditions: A meta-analysis. *Patient Educ Couns.* 2016; 99:706–717. [PubMed: 26613666]
29. O'Connor BC, Garner AA, Peugh JL, Simon J, Epstein JN. Improved but still impaired: symptom-impairment correspondence among youth with attention-deficit hyperactivity disorder receiving community-based care. *J Dev Behav Pediatr.* 2015; 36:106–114. [PubMed: 25650953]
30. The American Academy of Pediatrics. Implementing the key action statements: An algorithm and explanation for process of care for the evaluation, diagnosis, treatment, and monitoring of ADHD in children and adolescents. Vol. 2017. AAP; 2011.
31. Owens JS, Goldfine ME, Evangelista NM, Hoza B, Kaiser NM. A Critical Review of Self-perceptions and the Positive Illusory Bias in Children with ADHD. *Clin Child Fam Psychol Rev.* 2007; 10:335–351. [PubMed: 17902055]
32. White FA. Parent-adolescent communication and adolescent decision-making. *Journal of Family Studies.* 1996; 2:41–56.
33. Dunsmore J, Quine S. Information, support, and decision -making needs and preferences of adolescents with cancer: Implications for health professionals. *J Psychosoc Oncol.* 1995; 13:39–56.
34. Scherer DG. The capacities of minors to exercise voluntariness in medical treatment decisions. *Law and human behavior.* 1991; 15:431–449. [PubMed: 11660093]
35. McCabe MA. Involving children and adolescents in medical decision making: developmental and clinical considerations. *J Pediatr Psychol.* 1996; 21:505–516. [PubMed: 8863460]
36. Miller VA. Parent-child collaborative decision making for the management of chronic illness: a qualitative analysis. *Families, systems & health : the journal of collaborative family healthcare.* 2009; 27:249–266.
37. Miller VA, Jawad AF. Relationship of Youth Involvement in Diabetes-Related Decisions to Treatment Adherence. *Journal of clinical psychology in medical settings.* 2014

38. Schmidt S, Petersen C, Bullinger M. Coping with chronic disease from the perspective of children and adolescents--a conceptual framework and its implications for participation. *Child Care Health Dev.* 2003; 29:63–75. [PubMed: 12534568]
39. Modi AC, Pai AL, Hommel KA, et al. Pediatric self-management: a framework for research, practice, and policy. *Pediatrics.* 2012; 129:e473–485. [PubMed: 22218838]
40. McCabe SE, West BT, Cranford JA, et al. Medical misuse of controlled medications among adolescents. *Arch Pediatr Adolesc Med.* 2011a; 165:729–735. [PubMed: 21810634]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

### **What's New**

We determined the prevalence of reasons children and adolescents with ADHD stop and restart taking medicine. The most common reasons related to beliefs about the helpfulness of medicine. Functional impairments were common after stopping regardless of whether medication was resumed.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1

## Reason for Stopping

	% endorsed overall (N=286)	% endorsed by child (N=115)	% endorsed by adolescent (N=171)	p*
<b>Theme: Medicine Not Needed/Helping or Curious</b>				
I felt I could manage without it.	81.5	77.4	84.2	0.15
I wanted to find out if I could manage without it.	69.6	58.3	77.2	<0.001
I was doing so well I no longer needed it.	68.9	66.1	70.8	0.40
It was not helping me.	56.3	59.1	54.4	0.44
My parent(s) wanted to find out if I could manage without it.	45.5	53.0	40.4	0.03
My doctor wanted to find out if I could manage without it.	28.7	32.2	26.3	0.28
<b>Theme: Side Effects</b>				
It made me feel bad physically (e.g., nauseous, no appetite, thirsty, hard to sleep, shaky, tired, and/or mouth was dry).	48.6	46.1	50.3	0.49
It made me feel 'drugged' (e.g., 'zoned out,' lifeless, like a zombie, no personality).	41.3	40.9	41.5	0.91
It made me moody (e.g., irritable, angry, anxious, restless, and/or depressed).	34.3	33.0	35.1	0.72
<b>Theme: Logistics of Taking/Getting Medicine</b>				
I kept forgetting to take it.	25.5	16.5	31.6	<0.01
It cost too much.	6.6	7.0	6.4	0.86
Insurance stopped paying for it.	3.9	4.4	3.5	0.76
There was no doctor available to prescribe it.	3.9	4.4	3.5	0.76
My doctor refused to prescribe it anymore.	3.9	4.4	3.5	0.76
<b>Theme: Social Concerns/Stigma</b>				
It made it hard to make friends.	17.5	13.9	19.9	0.19
I felt embarrassed.	16.8	17.4	16.4	0.82
My friends didn't like me as much when I took it.	12.9	13.0	12.9	0.96
<b>Theme: Other Reasons</b>				
I was tired of taking it.	67.5	59.1	73.1	0.01
My parents decided to stop it.	31.8	48.7	20.5	<0.0001
I stopped for the summer.	28.3	20.0	33.9	0.01

\* Chi-square test or Fisher's exact test (if n<5 in any cell) for difference between % endorsed by child and adolescent

**Table 2**

## Reason for Restarting

	% endorsed overall (N=64)	% endorsed by child (N=15)	% endorsed by adolescent (N=49)	p*
<b>Theme: Medicine Needed/Helped</b>				
It helped me concentrate and/or focus in school or at work.	82.8	73.3	85.7	0.27
It made school and/or work easier (e.g., studied or worked longer, completed more work, and/or made it easier to understand what I read).	79.7	66.7	83.7	0.16
It helped me organize my thoughts.	67.2	60.0	69.4	0.49
I realized after stopping it that I needed to take it.	40.6	33.3	42.9	0.56
It stopped me from being impulsive.	37.5	60.0	30.6	0.03
It helped me concentrate when I drove (0 = do not drive).	12.5	13.3	12.2	1.0
<b>Theme: Logistics of Getting Medicine</b>				
A doctor became available to prescribe it.	20.3	13.3	22.5	0.72
Insurance started to pay for it.	14.1	6.7	16.3	0.67
<b>Theme: Other Reasons</b>				
I had planned to re-start after summer when school began.	57.8	46.7	61.2	0.32
My parents decided to re-start it.	53.1	66.7	49.0	0.26
I was allowed to decide when to take it (e.g., I could take it when I had a lot of work to do or at night when I needed to study).	39.1	20.0	44.9	0.13

\* Chi-square test or Fisher's exact test (if n = 5 in any cell) for difference between % endorsed by child and adolescent

**Table 3**

Assessment time point used to assess impairment after stopping medicine

<b>Follow-up Assessment Time Point</b>	<b>N</b>	<b>Mean age, years</b>	<b>SD</b>
2 year	15	9.9	0.8
3 year	8	11.2	0.9
6 year	54	13.8	0.9
8 year	38	16.0	0.9
10 year	28	17.9	0.8
12 year	24	20.2	0.5

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 4**

Impairment Ratings

	Parent Rating		Self-Rating		Diff <sup>3</sup>
	N	%	N	%	
<b>Columbia Impairment Scale<sup>1</sup></b>	<b>N=113</b>				
With schoolwork	92	81			N/A
With behavior at home	89	79			N/A
Getting along with siblings	77	68			N/A
Getting along with mother figure	77	68			N/A
With behavior in school	74	65			N/A
Getting along with father figure	66	58			N/A
Feeling unhappy or sad	61	54			N/A
Getting into trouble	60	53			N/A
With feeling nervous or afraid	58	51			N/A
Getting along with other kids own age	57	50			N/A
Getting along with adults other than parents	44	39			N/A
Getting involved in activities like sports or hobbies	40	35			N/A
With having fun	22	19			N/A
<b>Impairment Rating Scale<sup>2</sup></b>	<b>N=53</b>		<b>N=53</b>		
Your family in general	38	72	33	62	**
Self-esteem	38	72	23	43	**
Relationship with parent(s)	38	72	32	60	**
Relationship with other people his or her age	36	68	17	32	**
Academic progress at school	34	64	26	49	**
Functioning and overall need for treatment	33	62	24	45	**
Relationship with brothers or sisters	30	56	21	40	*
Performance at work	26	49	18	34	0.06
Relationship with his or her spouse or significant other	11	21	17	32	0.08
Your relationships with your co-workers			16	30	N/A



Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

	Parent Rating		Self-Rating		Diff <sup>3</sup>
	N	%	N	%	
Your relationships with your supervisors			13	25	N/A
Your relationships with teachers			14	26	N/A

<sup>1</sup> Collected at the 2, 3, and 6 year assessment time points, response options range from 0=No Problem to 4=Very Bad Problem, proportion with a response of 1, 2, 3, or 4

<sup>2</sup> Collected at the 8, 10 and 12 year assessment time points, response options range from 0=No Problem to 6=Extreme Problem proportion with a response of 1, 2, 3, 4, 5, or 6

<sup>3</sup> Diff = difference obtained from subtracting participant from parent ratings, Wilcoxon Signed Rank Test to determine if difference is significantly greater than zero

\* p<0.01;

\*\* p<0.001