Reasons Why Children and Adolescents With Attention-Deficit/Hyperactivity Disorder Stop and Restart Taking Medicine

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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% white) 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 of 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) adverse effects, 3) logistical barriers of getting or taking medication, and 4) social concerns or stigma. Seventeen percent (64 of 372) reported restarting medicine after stopping for a month or longer. Commonly endorsed reasons for restarting related to medicine being needed or medicine helping; and resolution of logistical barriers to getting or taking medicine. 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; adolescent; child; decision making

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What's New

We determined the prevalence of reasons children and adolescents with attention-deficit/hyperactivity disorder 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.

ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD) is the most common mental health condition of childhood,[1] affecting 6.4 million children aged 4 to 17 years in the United States.[2] Children with ADHD experience impairments across a wide range of areas of functioning, including academics, social relationships, and family functioning.[3] 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[4,5] and are recommended as a first-line treatment in clinical practice guidelines.[6]

Medication use is common among children with ADHD, but medication continuity is poor, as children often stop and restart medication in the first year of treatment.[7,8] Moreover, use declines markedly after age 11,[2] even though adolescents continue to demonstrate symptoms and functional impairment.[9] Teens who continue to take medicine take their medications inconsistently (ie, only 50% of days covered with medicine).[10] 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.[10–12] Given that medication has large effects on adolescent performance across a variety of domains (eg, academic tasks, social skills, vehicle-driving performance),[5,13–15] poor medication continuity represents a significant public health problem.

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Qualitative research has elucidated some reasons why children and adolescents with ADHD stop taking medicine.[16–22] For example, some do not believe that medication helps. Others do not like the way medication makes them feel. However, to our knowledge, no published reports 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 publicly available data from the Multimodal Treatment Study of Children With ADHD (MTA) prospective longitudinal cohort (MTA study identifier U01MH050453). Participants were originally recruited at 6 sites in the United States and 1 site in Canada. After a 14-month randomized clinical trial with 579 participants aged 7.0 to 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 (73.7%) of 579 participants at the 12-year follow up assessment point, when a survey was performed to assess the reasons behind stopping and/or restarting ADHD medication.[23] Previous analyses of adult outcomes indicated that MTA participants with and without complete data were not significantly different on most baseline demographic variables, and that "missing at random" criteria were met.[9] Of the 427 participants, 372 reported using ADHD medicine during their lifetime.

The current study included 296 participants who reported stopping (n = 286) and/or restarting (n = 64) ADHD medicine during childhood or adolescence (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 white, 19% were African American, 6% were Hispanic, and 9% reported more than 1 racial/ethnic category.

MEASURES

The MTA Cooperative Group developed the "ADHD Med Reasons" questionnaire. Items were drafted and iteratively refined on the basis of 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 (ie, response 1–3 = True, response 4–6 = Not true) and calculated the proportion endorsing each reason as true. Participants could endorse multiple reasons (Table 1). Participants were asked to complete

Table 1. Reason for Stopping Therapy

Reason	Endorsed Overall, % (n = 286)	Endorsed by Child, % (n = 115)	Endorsed by Adolescent, % (n = 171)	*P**
Theme: Medicine not needed/helping or curious				
I felt I could manage without it.	81.5	77.4	84.2	.15
I wanted to find out if I could manage without it.	69.6	58.3	77.2	<.001
I was doing so well I no longer needed it.	68.9	66.1	70.8	.40
It was not helping me.	56.3	59.1	54.4	.44
My parent(s) wanted to find out if I could manage without it.	45.5	53.0	40.4	.03
My doctor wanted to find out if I could manage without it.	28.7	32.2	26.3	.28
Theme: Adverse effects				
It made me feel bad physically (eg, nauseous, no appetite, thirsty, hard to sleep, shaky, tired, and/or mouth was dry).	48.6	46.1	50.3	.49
It made me feel 'drugged' (eg, 'zoned out,' lifeless, like a zombie, no personality).	41.3	40.9	41.5	.91
It made me moody (eg, irritable, angry, anxious, restless, and/or depressed).	34.3	33.0	35.1	.72
Theme: Logistics of taking/getting medicine				
I kept forgetting to take it.	25.5	16.5	31.6	<.01
It cost too much.	6.6	7.0	6.4	.86
Insurance stopped paying for it.	3.9	4.4	3.5	.76
There was no doctor available to prescribe it.	3.9	4.4	3.5	.76
My doctor refused to prescribe it anymore.	3.9	4.4	3.5	.76
Theme: Social concerns/stigma				
It made it hard to make friends.	17.5	13.9	19.9	.19
I felt embarrassed.	16.8	17.4	16.4	.82
My friends didn't like me as much when I took it.	12.9	13.0	12.9	.96
Theme: Other reasons				
I was tired of taking it.	67.5	59.1	73.1	.01
My parents decided to stop it.	31.8	48.7	20.5	<.0001
I stopped for the summer.	28.3	20.0	33.9	.01

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

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