

Parental Angst Making and Revisiting Decisions About Treatment of Attention-Deficit/Hyperactivity Disorder



WHAT'S KNOWN ON THIS SUBJECT: Initiation of medication for ADHD is variable and persistence with therapeutic regimens is poor. Parents play a key role in managing medication use for their child with ADHD.



WHAT THIS STUDY ADDS: This study identifies factors that influence parent decision-making about the initiation and continuation of medication treatment. Awareness of these factors may help physicians address the concerns of families while managing ADHD.

abstract

BACKGROUND: Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurobehavioral conditions of childhood and adolescence. Despite availability of effective treatment options, initiation of treatment is variable and persistence with therapeutic regimens is poor.

OBJECTIVE: We sought to better understand how parents make decisions about treatment for their child or adolescent with ADHD.

METHODS: We conducted a qualitative study among parents of children and adolescents; 52 parents participated in 1 of 12 focus groups. Parents answered questions about decision-making, information sharing, and sources of conflict and uncertainty. Sessions were audiotaped and transcribed verbatim. Themes were coded independently by 4 of the investigators, who then agreed on common themes.

RESULTS: Parents in our study made decisions about treatment for their child with ADHD in the midst of experiencing a variety of emotions as they witnessed child functional impairments at home and at school. In addition, parents felt stress as a result of their daily efforts to manage their child's struggles. Multiple factors influenced the decision to initiate medication. Subsequently, revisiting the decision to give their child medicine for ADHD was common. Many parents contrasted time on and off medicine to help inform management decisions. Trials stopping medication were almost always parent- or child-initiated.

CONCLUSIONS: Decisions about medication use for children and adolescents with ADHD are made and frequently revisited by their parents. Choices are often made under stressful conditions and influenced by a variety of factors. Striking a balance between benefits and concerns is an ongoing process that is often informed by contrasting time on and off medication. Development of strategies to support families across the continuum of decisions faced while managing ADHD is warranted.

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CONTRIBUTORS: William B. Brinkman, MD, MEd,^a Susan N. Sherman, DPA,^b April R. Zmitrovich, MPH, MSW,^a Marty O. Visscher, PhD,^a Lori E. Crosby, PsyD,^a Kieran J. Phelan, MD, MsC,^a and Edward F. Donovan, MD^a

^aDepartment of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; ^bSNS Research, Cincinnati, Ohio

KEY WORDS

ADHD, family/self-management, parent decision-making, adherence, treatment

ABBREVIATION

ADHD—attention-deficit/hyperactivity disorder

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Address correspondence to William B. Brinkman MD, MEd, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave, ML 7035, Cincinnati, OH 45229-3039. E-mail: bill.brinkman@cchmc.org

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Attention-deficit/hyperactivity disorder (ADHD) is a common neurobehavioral disorder that affects children and adolescents.¹ ADHD results in impairment of academic, social, and family functioning. Parenting a child with ADHD is stressful^{2,3} and can lead to feelings of inadequacy and self-blame.^{4–6} In addition, different conceptualizations of ADHD among parents can be a source of conflict as fathers more often than mothers tend to resist the label of ADHD and treatment with medication.^{4,5,7–9} Similar to other pediatric chronic conditions, parents play a key role in implementing treatment plans that are made during visits with their child's doctor. Despite the efficacy of medication to reduce ADHD symptoms,¹⁰ medication initiation is variable,¹ and medication continuity is poor because many children stop taking medicine and/or have extended gaps in medication supply.^{11,12} Although studies have identified child characteristics (eg, age, race)^{11–16} and medication management factors (eg, dosing regimen)^{11,16} related to medication continuity, factors that influence family decision-making have not been fully elucidated. The objective of this study was to better understand how parents make decisions about treatment for their child or adolescent with ADHD. We used qualitative research methods, because they are often useful in exploring complex, multi-faceted questions that may not be readily understood by more direct, close-ended quantitative survey methods. The methods were used to generate a theoretical framework for how parents approach ADHD treatment decision-making and not to test specific hypotheses.^{17–19}

PARTICIPANTS AND METHODS

With Cincinnati Children's Hospital Medical Center institutional review board approval, we conducted 12 focus groups with parents of children

and adolescents with ADHD in July and August of 2006.

Sample

Parents were eligible to participate if their child had been diagnosed with ADHD, was between the ages of 6 and 17 years, and had been seen for ADHD in the past 2 years at 1 of 10 community-based pediatric practices in the Cincinnati/Northern Kentucky region. Children ($n = 3596$) were identified through a billing database. We stratified by gender and age (6–9, 10–12, 13–15, and 16–18 years of age) and randomly sampled an equal number from each stratum. This procedure enhanced sample variability by ensuring that parents of boys and girls at a full range of ages would have an equal opportunity to participate. Subsequently, parents ($n = 233$) received a letter from their child's doctor inviting them to participate in the study. Thirteen parents indicated that they did not want to be contacted. The remaining parents received a follow-up telephone call. Ninety-eight parents could not be reached. Of the parents contacted by telephone ($n = 122$), 71% expressed interest in participating. Secondary telephone screening ensured that the sample included only the "parent" (eg, biological parent, legal guardian, etc) who identified herself or himself as the child's primary caregiver to ensure that participants had relevant experience making ADHD treatment decisions.

Data Collection

During recruitment, each parent answered a brief telephone screening questionnaire that included questions about the diagnosis and treatment of their child with ADHD as well as demographics. Parents provided written informed consent before participating in the focus group. Focus group sessions were held at Cincinnati Children's Hospital Medical Center and 3 community-

based outpatient centers. The focus groups averaged 1.5 hours in duration and were audiotaped. Each parent was reimbursed \$50 for their time and travel expenses.

Focus groups were led by 1 of the investigators (Dr Sherman), an experienced focus group facilitator. The prompting questions used in the focus groups were developed during group meetings with all investigators and informed by the extant literature. Broad, open-ended questions were followed by more specific, probing questions to clarify the participants' responses and to narrow the discussion. The questions were designed to explore parent experiences making decisions about management of their child with ADHD. The question guide was modified slightly in an iterative process as the focus groups progressed to accommodate new issues that were raised by parents. A consensus was reached by the investigators that thematic saturation (ie, point at which new observations yielded no new information to challenge or elaborate the framework)^{17,20} was achieved by the conclusion of the 12th focus group and recruitment was terminated. Therefore, 52 of the 122 eligible and interested parents participated in the study. A copy of the focus group guide is available on request.

Data Analysis

Each focus group session was transcribed verbatim and entered in a computerized transcript database. We used a grounded theory approach to our data,²¹ whereby 4 investigators (Drs Brinkman, Sherman, and Visscher, and Ms Zmitrovich) read the transcripts and collaboratively identified emerging themes. Then, through group sessions, we labeled themes and constructed a codebook. Each reader then independently coded parent responses using the codebook.

Group meetings were held to discuss the codes assigned to statements and to arrive at consensus. Use of >1 investigator to analyze the raw data, such that the findings emerge through consensus between investigators, is a method to prevent the personal or disciplinary biases of a single researcher from excessively influencing the findings.^{17,20,22} A total of 501 unique supporting comments corroborated 8 major and 33 minor themes. By using the transcript database, the investigators generated a list of all verbatim quotations supporting each of the themes and together selected the most representative comments for presentation here ($n = 71$).

RESULTS

A total of 52 parents participated in 1 of 12 focus groups. Participant characteristics are presented in Table 1. Parents were predominantly mothers (82%), although 4 fathers, 3 grand-

TABLE 1 Participant Characteristics

	<i>n</i> (%)
Age of parents, y	
<19	0
20–29	5 (9)
30–39	19 (37)
40–49	18 (35)
50–59	9 (17)
60–69	1 (2)
Ethnicity	
Hispanic	0
Non-Hispanic	52 (100)
Race	
White	39 (75)
Black	13 (25)
Education	
≤8th grade	0
Some high school	4 (8)
High school graduate/GED	13 (25)
Technical or trade school	1 (2)
Some college	11 (21)
Associate's degree	4 (8)
College degree	16 (30)
Graduate degree	3 (6)
Child gender	
Male	31 (60)
Female	21 (40)
Years since child was diagnosed with ADHD, mean (SD)	4.4 (3.7)

GED indicates general equivalency diploma.

mothers, 1 aunt, and 1 foster parent also participated. Self-reported race of participants was similar to the Cincinnati/Northern Kentucky general population; 32% reported a high school education or less. Nearly all children (96%) had tried medicine for ADHD.

The themes and representative verbatim quotes are presented in Tables 2, 3, and 4.

Domain 1: Context of Decision-Making—Parent Stressors

Table 2 delineates the emotional context of decision-making for parents of children with ADHD. The themes of parental self-doubt, daily struggles at home and school, parental conflict with each other, and the emotional burden of decision-making impact the process parents experience in making treatment decisions for their children.

Parents experience a wide and complex variety of stressors as they decide how to help their child with ADHD. Many parents begin to doubt their parenting skills and/or blame themselves for the difficulties encountered by their child (theme 1). Parenting skills are challenged on a daily basis and parenting becomes very taxing and largely punitive rather than rewarding (theme 2). Many parents have stressful conflicts with their child about homework completion and following instructions. Stress also results from the sheer amount of effort required to parent a child with ADHD and the ineffectiveness of those efforts. Parents report that issues surrounding their child's struggles at times permeate their immediate and extended families and often their personal lives, resulting in tumult, dissension, and dysfunction. In addition, parents are stressed by their child's struggles at school and/or feel external pressure from school personnel to take action (theme 3). For some parents, ADHD is a

divisive issue, with mothers and fathers coming to different conclusions about the nature of their child's behavior and the appropriateness of treatment (theme 4). Parents experience a gamut of emotions when deciding about treatment for their child with ADHD. Emotions include anger, disappointment, desperation, and ambivalence (theme 5). Some parents identified 1 of these stressors, whereas others cited the cumulative effect of multiple stressors.

Domain 2: Factors That Influence the Decision to Initiate Medication (Table 3)

Many factors influence whether parents choose to initiate medication for their child with ADHD. Parents described factors that supported the initiation of medicine (theme 6a) as well as factors that delayed their decision to do so (theme 6b). These factors are contrasted in Table 3. Recognition that their child is suffering from functional impairments is a key factor that prompts parents to initiate medication. Many parents stated they had been in denial that their child had a problem. Communication with the child's teacher impacted problem recognition for many parents. Parents reported that acceptance of the diagnosis of ADHD was an important factor. Stories from personal and/or third party experiences with ADHD and medication are often influential. Physician and family support are very influential factors as well. Information from a variety of media was also important. For some parents, espousing belief in a biomedical model for ADHD facilitated initiation of medication. For others, concern about stigma was a barrier to treatment. Parents also reported many concerns that delayed initiation of medication, including a general reluctance to use medicine, the belief that medicines should not be relied on as a solution for behavioral problems,

TABLE 2 Domain 1: Context of Decision-Making—Parent Stressors

Theme 1: Parent self doubt and blame regarding child's struggles

"It's very frustrating because you are pulling your hair out thinking, 'What have I done wrong? What is wrong with him?' I am a mother, why can I not fix this?"

Theme 2: Daily struggles parenting child with ADHD

"I think a lot of parents don't even understand the level of effort that you have to go through to work with a kid who has ADD or ADHD. It is parenting times 10. It is a lot more effort and a lot more work."

"Sometimes I was like, 'Please somebody help me.' I don't want to hit him, but I am this far from hitting him. Please sit down. I would sit and hold him in my arms to keep him still."

"I was in tears because it was really hard. On the brink of losing my job, going to school all the time. It was very, very hard."

"If I said tie your shoe and then I said tie your shoe, put your coat on, and brush your hair. Lord have mercy! He wasn't even tying his shoe . . . what would end up happening—all of us—would be a team, my daughter, my husband, and myself . . . all squeezed into the bathroom . . . working on him . . . one person . . . brushing his teeth, the other person washing him . . . somebody else would be putting his underpants on . . . this is not working."

"We needed to feel like a family, and we fought all the time and everything was hard."

Theme 3: School pressure

"When they kept calling me at school, calling me at work, I had to change my shift a few times. I went to third shift. I took him to school and I sat in class with him . . ."

"It was like the teachers were pushing me, pushing me. Get him meds, get him meds."

Theme 4: Conflict between parents about diagnosis and/or treatment of ADHD

"Well, I was basically more for it than my husband. My husband thought, 'Here we are drugging up this kid.' . . . [husband thought] 'He's just an active boy. He's just a boy.'"

"I think that the reason my husband disagreed is because . . . he had the same problem and he was not put on medication . . . so he decided our son is not going on medication. He has to learn to cope."

"I had that problem with my ex-husband. He told my daughter that if she take that medicine, she'll be a crack head."

". . . She visits him [her father] every other weekend. . . . He will say, 'Don't want to take your medicine today? Okay, don't take it' . . . It's a big thing. I don't get support from the other half."

Theme 5: Parent emotional burden of decision-making

"I was close to having a nervous breakdown. Like you say, you cry, you're angry. That's how I felt. You cry because this is my child. What can I do? Punish him, spanking him, putting him in the corner. That stuff was not working. That broke my spirit. It really took me all the way down for me to say, 'You know what, I got to do something.'"

"I was to the point where, honestly, I loved my daughter but I did not like her. I did not want to feel that way, so I had to do something. . . ."

"You are always making those decisions and choices and things for your child, but then you're faced with . . . I know they have this issue, how much are you helping them, hurting them? You are never really gonna know."

and fears about drug addiction and adverse effects. Facilitators of medication initiation included failure of non-medication treatment modalities, parent awareness of potential long-term consequences of ADHD, and viewing stimulants as an established medication. Viewing the initiation of medication as a time-limited trial was a strong facilitator. Many parents reported that their child's doctor introduced the idea of trying medicine for a month to see if it would be helpful for their child. This approach reduced anxieties for many parents. Parents report that experiences during the trial of medicine help to inform subsequent decisions about whether to continue medication. Perceived benefits were weighed against the adverse effects experienced. For some, the decision to continue medicine became easy, because the benefits far outweighed the adverse effects. For others, uncertainty

persisted as they tried additional doses and/or medications after experiencing inadequate benefit or intolerable adverse effects. This led to frustration and disillusionment about medication treatment for some families.

Domain 3: Continued Doubt and Uncertainty (Table 4)

Many parents reported revisiting the decision of whether to keep giving their child medication for ADHD (theme 7). Many parents had lingering concerns about medication despite perceived efficacy. Some parents revisited the decision because of conflicts with their child about taking medicine. Many parents wondered how long their child would need medication with some hoping their child would outgrow ADHD and others worried that the need for medication would continue. Many parents reported uncertainty about the continued need for medication.

An unexpected theme that emerged from the focus groups was that many parents reported that contrasting their child's experiences on and off medication helped inform decisions about whether to persist with medication (theme 8). This theme was not a part of the interview guide, yet it appeared as parents spontaneously shared their thoughts about revisiting decisions. For some, time off medicine was unintentional and the result of their child forgetting to take the medicine. For many, medicine was intentionally discontinued as a trial to see if the child still benefited from the medicine. Parents reported trials stopping medicine that were doctor-, parent-, and child-initiated. It is noteworthy that such trials were seldom coordinated by the child's doctor. Trials stopping medicine convinced some parents of their child's continued need for treatment, whereas

TABLE 3 Domain 2: Factors That Influence the Decision to Initiate Medication

Theme 6a: Factors That Support Initiation of Medication	Theme 6b: Factors That Delay Initiation of Medication
<p>Parent recognition of child functional impairments</p> <p>“... as she got older it was more apparent that I did really need to treat her symptoms to make her function in the classroom better, to feel better about herself, and more functional in our home and even outside our home, socially with peers or anyone, it had to happen.”</p>	<p>Parent denial that their child has a problem</p> <p>“I think I kind of fought it tooth and nail. I just kept comparing him to other boys, in my mind thinking he’s just active. I didn’t think there was anything wrong with him.”</p>
<p>Teacher identified problem</p> <p>“His teacher is the one who noticed it. He couldn’t focus on the board.”</p> <p>“His [preschool] teacher helped me out because he wouldn’t sit still... She called me and said, ‘I think your son has ADHD.’”</p>	<p>“... I found it hard to believe that he was as bad as they were all saying he was in school. I mean bad not in terms of behavior, but just complete inability to function in the classroom.”</p> <p>Poor communication with teacher</p> <p>“At the end of the year I got a little folder and daydreaming was written all over it. The teacher never said anything to me about it.”</p> <p>“... the teacher didn’t say ‘I think he has this’, but, ‘You should really work on a lot of reading and all of that.’ I had this feeling she was trying to tell me something but she wasn’t really allowed to.”</p>
<p>Acceptance of diagnosis</p> <p>“... Acceptance of the diagnosis. It was a relief that we know what we’re treating and know that what we are going [to do] is the right thing.”</p>	<p>Lack of confidence in diagnosis</p> <p>“We struggled and are still struggling with the diagnosis. She carries that label of ADD, but we are not entirely sure.”</p>
<p>Story or experience that supports treatment with medicine</p> <p>“I think part of the reason I was not averse to medicine is that my cousin has a child who is 5 years older than my son who is ADD and I saw how it helped [him].”</p> <p>“For me, it helped talking to other parents. I talked to a lot of parents that did use medication and it seemed to help their child.”</p>	<p>Story or experience that opposes treatment with medication</p> <p>“I had a niece on [medication] who was more like a vegetable, didn’t want to eat, talk, play, nothing.”</p> <p>“The side effects of the drugs and all the horror stories that you hear. His mom [child’s grandmother] is a nurse, and so I hear it all the time. She doesn’t agree with the medicine.”</p>
<p>Positive relationship with child’s doctor</p> <p>“I had such confidence in my doctor. We talked it through for such a long time.”</p> <p>“The first thing he [pediatrician] said to me was, ‘I want you to calm down. You are not a bad parent.’ I actually didn’t expect that. I sort of expected him to be like, ‘Here’s the problem. Here’s how we are going to manage it.’ He was actually more comforting to me than anything.”</p>	<p>Lack of physician support and/or trust</p> <p>“I felt intimidated by him because I knew he talked basically and he didn’t want to hear any questions from you.”</p> <p>“A lot of times I feel ignored... I have read, I have researched... when I am sitting here trying to talk to you [pediatrician]... you are not listening to me.”</p>
<p>Extended family support</p> <p>“My mom and dad are my support system. Basically, whatever decisions I tend to make, they stand behind me.”</p> <p>“My Dad was very adamant that we get her on medication, because I was on Ritalin as a child, my little brother was on Ritalin, and he saw it really seemed to help us.”</p>	<p>Lack of support from relatives</p> <p>“Me, I had to hear from my family members. They [are] more old school and no medicine. Especially my mother [who says], ‘All he needs is a stiff butt whipping.’”</p> <p>“I got really irritated with a few friends and family that—Gasp! You put your daughter on medicine!! How could you do such a thing?”</p>
<p>Other information sources that support treatment with medicine</p> <p>“I went to the library and got books about it. I read and it was definitely my son.”</p> <p>“When I got on some Web site that had a lot of conversation, people’s input, I said, my son needs help beyond the things we are doing nonmedication.”</p>	<p>Other information sources that oppose treatment with medicine</p> <p>“I think through the years they had too many things in magazines and so many things on television that scare you half to death when it comes to Ritalin. You don’t want to do anything to harm your child and you are at a disadvantage, because you are not part of the medical community. You have to rely on your doctor.”</p>
<p>Parent belief in biomedical model of treatment for ADHD</p> <p>“I guess I am more open to the medication because I’ve been on thyroid medicine since 1992, and I know how I can’t function to my best abilities if I don’t take it... why would I deny my child a medicine that’s gonna help them get through life?”</p>	<p>Stigma</p> <p>External stigma: “I don’t want my child or anyone else’s child to be labeled.”</p> <p>Internal stigma: “She just feels different, because she knows she has to take [medicine] every day and most kids don’t.”</p>
<p>Failure of other treatment modalities</p> <p>“I think that there was an element of disappointment that we had to resort to medication... We wished that we had been able to somehow find a way to manage this without medication, but clearly, that’s not the case. We’ve done our best, given it our best shot. [Son] is still suffering. We are gonna give it a trial of medication.”</p>	<p>General reluctance to use medications</p> <p>“I was scared. What have I done? It’s like, I know my child is suffering, but drugs? Is there another way?”</p> <p>“Giving your child medication that affects their brain. I was pretty scared about it and still am. There is still a part of me that thinks I don’t care that kids have been on this for 50 years, I don’t like it.”</p>

TABLE 3 Continued

Theme 6a: Factors That Support Initiation of Medication	Theme 6b: Factors That Delay Initiation of Medication
Awareness of potential long-term consequences of unmedicated ADHD "He [child's father] didn't even make it through school. It's ruined his life. Had no recognition of it back in those days. . . . He was punished all the time, because he was always in trouble."	Parent concern about relying on medicine to fix things "My feeling is that I don't want her, even though she is young, to think that she can pop a pill and the world is going to be okay. Medicine is gonna take all the pain away and make everything better." "It scared me. I was just terrified that I had to depend on a drug for my child to act right."
Stimulant viewed as established medicine ". . . Ritalin, as we found out, has been around for so long—50 years. I felt like it was probably more safe than these new asthma/allergy medicines."	Parent concern about drug addiction "We've got drug addicts in our family. . . . I don't want her to get used to popping pills. . . . I've got a sister that does that."
Initiation of medication viewed as a time-limited trial "I didn't feel locked into it. My doctor said, 'Let's try it. Let's give it some chance to see if it will help him.' So then I felt more comfortable." "It seems it would be a good idea to dip your toe in the water to see how it feels before you jump into the pool."	Parent concern about medication side effects "He gave me a pamphlet on Adderall and another med and it affects your liver. I am not putting my babies on [medicine]. One affects his liver and the other makes him psychotic; I can't do that." "It's scary, because what will happen 30 years down the road?"

TABLE 4 Domain 3: Continued Doubt and Uncertainty

Theme 7: Medication decisions revisited "Was I doing the right thing? That was the hardest part. Putting him on, am I doing the right thing? Taking him off, am I doing the right thing?" "To this day, we remain, for lack of a better word, nervous about medicating someone that young on a long-term basis." "I just seen improvements at home as far as focusing. I didn't have to tell him one by one to do this, to do that. It was amazing. But still, the drug thing, I am iffy, but he's doing a lot better." "I really didn't want to feel that I was making her do something she didn't want to do, in that way. I didn't want her to feel I was forcing drugs into her." "My husband was ADD when he was younger and ~13 years old, he outgrew it. That's one thing I am hoping for that when he gets a little older, that he'll outgrow it." "This is 6th grade, and it's gonna be getting tougher. I am just really leery of even trying him without medication but then I keep thinking, 'Am I doing the right thing?' That doubt is always there." "I just want to know how to differentiate. Does he really need it or is it okay to take him off? He reminds me now to take his medicine. It's like a routine to him. I want to know if he can really do it on his own." "When [medication] first started, for that first 6 months, I was happy about it. But then, after that, that's when it started playing in my mind about addiction."
Theme 8: Trials stopping medicine Forgetting: unintentional trials off medicine Success: "There have been days when she has forgotten to take it and she has done real well on a test. Who knows?" Failure: "I noticed a huge, bad, 4 to 5 steps backwards for the one day that she's not on it. I was surprised how obvious it would be that one day that she forgets it." Doctor initiated trials off medicine "We have done this about every year, along with the pediatrician. But he wants it to be consistent, normal time. Not over Easter break. Give it maybe a month or two off the medication to see how it works. We have done it several times, and we have always went back on the medicine." Parent-initiated intentional trials off medicine Success: "I decided I am not gonna give him the medicine tomorrow and see what he does. I didn't give it to him. He went to school. I waited by the phone all day long. The phone didn't ring. Next day I did the same thing, waited by the phone, phone didn't ring. I thought I am going up to the school this evening and talk to the teacher when school gets out. When I got up there she said, 'I don't know what you did, but he has completely turned around.' Failure: "We'd try to take her off and the teacher would write back, 'What's going on? Behavior is different, attention is different.' We tried to see if the other stuff had kicked in. . . . to see if the organizational stuff had kicked in." "Later on when I got some anxieties about it and I backed off the medicine for a while, the phone rang off the hook and I had to give it to her."
Child-initiated intentional trials off medicine Success: "He quit taking it in high school, because he just didn't feel it was helping him. Every once in a while we would try it and see how it works. He would go on for a little bit and said, 'I just don't really see a difference.' So he didn't take it." "After he took it for a little bit and he just didn't like the way it made him feel, so he asked if he could go off of it. With me being kind of reluctant with it, we made the deal, 'If you can keep your grades up and you can stay focused, then that's fine.'" Failure: "My son actually started talking about wanting to stop taking the medicine. That was another test we had to just see. I thought if I can navigate him through it, we'll be okay. When he flipped back and said, 'I think I need it,' I was like, 'Great.'"

others found that their child could function well without medicine. Regardless, the trial lessened parent uncertainty about the proper course of action.

DISCUSSION

Parents in our study made decisions about treatment for their child with ADHD in the midst of experiencing a

variety of emotions as they witnessed child functional impairments at home and at school. In addition, parents felt stress as a result of their daily efforts to manage their child's struggles. Mul-

tiple factors influenced the decision to initiate medication. Subsequently, revisiting the decision to give their child medicine for ADHD was common. Many parents contrasted time on and off medicine to help inform management decisions. Trials stopping medication were almost always parent- or child-initiated.

This study has several limitations. First, the findings were from a sample of mainly mothers who were white or black. Also, nearly all parents had tried medicine for their child with ADHD. Perspectives may or may not differ from those of fathers or parents of other cultural backgrounds and parents who do not initiate medication. In addition, it is difficult to separate parent views of diagnostic uncertainty, labeling terms, and conceptualization of the disorder, because these feelings and perceptions coalesce and impact decisions about treatment. Qualitative research offers a rigorous alternative to armchair hypothesizing in areas for which insight may not be well established or for which conventional theories seem inadequate.¹⁷ In this case, what was not well understood was how parents make decisions about treatment for their child or adolescent with ADHD. Using focus groups, we probed, in-depth, the perspectives of a group of parents of children and adolescents with ADHD. Interpretations of the parents' statements were made by consensus of a group of readers with varying perspectives. Together, the authors developed an explanation of how parents make ADHD treatment decisions. This study was not meant to produce any conclusion about the phenomenon under study that could be generalized to all parents of children with ADHD. Opportunities exist for quantitative investigations to test the implied hypotheses about relationships between variables identified that influenced parents in our study.¹⁷

It is possible that the group setting may have inhibited some parents from participating in these focus groups. It is also possible that parents who struggled were more likely to choose to participate. For many parents the group discussion seemed to have a cathartic effect. Some parents yielded an unanticipated source of support as they exchanged information about ADHD-related resources and/or exchanged telephone numbers after the focus group concluded. Despite these limitations, this study suggests that a variety of factors influence the decision to initiate medication. Our analysis of parent comments corroborates previous work in this area and provides a far more comprehensive collection of factors than previous studies.^{4-7,23-35} Previous efforts implementing the American Academy of Pediatrics clinical practice guidelines for the diagnosis and treatment of ADHD demonstrated a need to augment the time-constrained efforts of physicians to educate and support parents.³⁶ Future studies are needed to develop and test systems to support parents facing treatment decisions for their child newly diagnosed with ADHD.

After initiating treatment, stopping and restarting medicine for ADHD is common.^{11,37,38} Qualitative methods, such as those employed in the current study, are essential to develop a richer understanding of this phenomenon. Parents in the current study and others^{6,7,39,40} continue to experience fears and worries related to the potential for long-term adverse effects, even if their child shows marked improvement. This phenomenon is especially pertinent given ongoing public discussion of the effect of stimulant medications on growth^{41,42} and the possible linkage between sudden cardiac death and the use of ADHD medications.⁴³⁻⁴⁷ Past and present experience of adverse effects is also a cause for concern. In some

cases, lack of child willingness to take medicine is a significant challenge. It is noteworthy that child refusal to take medication continues to be a significant issue despite the advent of extended release preparations that eliminate the need for a daily visit to the school nurse's office and thereby remove much of the stigma of taking medication for ADHD. Parents weigh medication concerns and challenges against the functional improvements seen at home and at school. It is expected that children and adolescents and their parents question whether their goals can be achieved without medication. Contrasting time on and off medication is a rational way to inform decisions about the continued necessity of treatment. Although this may run counter to traditional ideas about "adherence" and lead to some second guessing for those whose problems recur off medication, such trials are likely to reduce a great deal of anxiety and uncertainty on the part of children and adolescents, their parents, and physicians.

Given the low rates of ADHD medication follow-up that have been documented,⁴⁸⁻⁵² it is not surprising that parents in this study rarely reported physician involvement in trials stopping medication. To our knowledge, there are no estimates in the literature for how often physicians coordinate such trials. The American Academy of Pediatrics clinical practice guideline for the treatment of ADHD⁵³ emphasizes the importance of ongoing monitoring of target outcomes and adherence to the treatment plan, but does not explicitly discuss trials of medication discontinuation. Recently, authors of the Multimodal Treatment Study of ADHD in Children have recommended this practice to determine if there is continued need for medication or if symptoms have remitted.^{54,55} Recently updated ADHD treatment guidelines from the Ameri-

can Academy of Child and Adolescent Psychiatry⁵⁶ and the Institute for Clinical Systems Improvement⁵⁷ provide guidance for the conduct of such trials stopping medication: “(1) consider annually when stable and doing well; (2) best when there are few transitions or demands (eg, mid-school year); (3) avoid at beginning of any school year, especially at the start of junior/senior high school; and (4) try discontinuing medications for 2 to 4 weeks with close monitoring of target outcomes.” Anecdotally, some families who stop treatment on their own face a crisis (eg, school failure, delinquency, etc) before they resume medication. This begs the question, how much struggle is necessary to raise awareness of the continued need for medicine? Future studies should test whether physician-directed trials of medication discontinuation can identify children and ado-

lescents with ADHD who continue to suffer from functional impairments in a timely manner and avert undesirable outcomes. Studies are also needed to identify additional reasons why children with persistent ADHD symptoms stop and/or restart medication treatment. The current study elicited the parent perspective on ADHD treatment decision-making. Additional studies are needed that elicit the perspectives of children and adolescents with ADHD as well as the views of their primary care doctor.

CONCLUSIONS

This study provides evidence that decisions about medication for children and adolescents with ADHD are made and frequently revisited by their parents. Choices are often made under stressful conditions and a variety of factors influence these decisions.

Striking a balance between benefits and concerns is an ongoing process that is often informed by contrasting time on and off medication. Development of strategies to support families across the continuum of decisions faced while managing ADHD is warranted. Future studies are needed to determine the efficacy of such interventions and guide their implementation in clinical practice.

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