

# The Meaning of Attention-Deficit/Hyperactivity Disorder Medication and Parents' Initiation and Continuity of Treatment for Their Child

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## Abstract

**Objective:** The aim of this study was to examine parents' early understanding of medication for attention-deficit/hyperactivity disorder (ADHD) in relation to decisions to initiate and continue treatment for their child.

**Methods:** Qualitative, semistructured telephone interviews were conducted with 48 parents of children newly diagnosed with ADHD. Parents were recruited from inner city, outpatient primary care, and mental health clinics affiliated with a large university hospital. Data were analyzed using grounded theory.

**Results:** Parents' initial perspectives of the appropriateness, anticipated effects, and symbolic meaning of medication were classified by four typologies (illness oriented, problem oriented, generally acceptable, unacceptable). In this sample, 29% of parents believed medication was required to treat the illness and 20% believed medication was unacceptable. Except for the unacceptable group, nearly all of the parents in the other groups initiated medication shortly after diagnosis. More than 80% of the illness- and problem-oriented groups used medication at 6 months; this fell to 64% and 78%, respectively, at 12 months. Only half of the unacceptable group ever used medication for their child.

**Conclusions:** Parents' views of ADHD medication may be predictive of continuity of treatment. Increasing physician awareness of parent preferences for managing their child's ADHD problems may lead to care management plans that maximize continuity.

## Introduction

PARENTS ARE GENERALLY RELUCTANT to initiate medication treatment for their child's attention deficit/hyperactivity disorder (ADHD). Although some parents readily accept medication as the primary treatment (Leslie et al. 2007) and are satisfied with behavioral and academic improvement (Rostain et al. 1993; Bussing et al. 1998; Corkum et al. 1999; dosReis et al. 2003; dosReis et al. 2006; Olaniyan et al. 2007), hesitancy to use stimulants arises from what parents hear from family and society. This is particularly true among families living in low-income, inner-city communities (dosReis et al. 2003; Guevara et al. 2005; dosReis et al. 2006; Olaniyan et al. 2007). Oftentimes, medication is a last resort after exhausting all other options (Rappaport and Chubinsky 2000). Views about the appropriateness and anticipated effects are strong predictors of willingness to use

psychiatric medications for themselves or children (Croghan et al. 2003; McLeod et al. 2004). This is probably best understood by how people view illness (van der Geest and Whyte 1989) and by their expectations for treatment (Shuman and Shapiro 2002; Meyer et al. 2002). Medication use inherently sets people apart from those who are 'not ill' and avoiding medication may reflect an attempt by individuals to maintain their 'non-ill' identity (Scherman and Lowhagen 2004). Parents of children with ADHD create their own understanding of the disorder (Mychailyszyn et al. 2008), and this is further differentiated between those whose children receive ADHD medication as compared to parents whose children do not (Borden and Brown 1989; Johnston and Freeman 1997). Sociocultural factors also influence how parents come to terms with their child's ADHD (dosReis et al. 2007) and when they decide to seek medication treatment (Leslie et al. 2007).

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Unfavorable views may ultimately lead parents to use treatments that have less evidence of effectiveness (Johnston et al. 2005). Acceptability is typically lower when individuals are not comfortable with a medical approach (Heisler et al. 2003; Brown et al. 2005). Knowledge of parental attitudes and approaches to their child's treatment could help providers better engage them in care (Metzl and Riba 2003). However, little is known about how parental views guide their treatment decisions and influence continuity of treatment. The goals of this study were to: (1) Identify the relationship between parents' conceptualization of medication, before their child was diagnosed with ADHD, and their decision to use medication for their child, and (2) explore the connection between parents' views of medication and their continuity of treatment.

## Methods

### *Study design*

This was a qualitative study with a 12-month follow up of treatment for ADHD. Semistructured telephone interviews were conducted with 48 parents within 1 month after their child received an initial diagnosis of ADHD. Diagnoses of ADHD and other psychiatric co-morbidities were obtained using the provider's clinical assessment that was noted in the medical chart because the epistemological basis of qualitative research is to assess individuals' experiences in a naturalistic setting. Parents were eligible if their child was between the ages of 6 and 18. The Johns Hopkins Medicine Institutional Review Board approved the study protocol.

### *Subject recruitment*

Participants were recruited between November, 2003, and December, 2006, from primary care, developmental/behavioral pediatrics, and specialty mental health clinics affiliated with a large teaching hospital in Baltimore, Maryland. The outpatient clinics were targeted purposefully to capture parents from a range of settings where they initially sought care for their child's ADHD. Of the 69 invited to participate, 48 (70%) joined the study and were interviewed. The proportions across each site were: 33% ( $n = 16$ ) primary care, 48% ( $n = 23$ ) developmental/behavioral pediatrics, and 19% ( $n = 9$ ) specialty mental health clinics.

Clinicians identified eligible parents during a child's scheduled appointment and presented them with a brochure describing the study. Parents interested in the study met with a member of the research team to discuss the study protocol. For those agreeing to participate, written informed consent was obtained from the parent; adolescents 12–18 years old provided written assent, and verbal assent was obtained from children ages 6–11.

### *Interview procedure*

Interviews were conducted by telephone. Two exceptions were made for parents who requested a face-to-face interview, which was scheduled to coincide with the child's clinic appointment. These interviews were conducted in a private room in one of the outpatient clinics.

Semistructured interviews inquired about parents' general understanding of their child's problems and the ADHD diagnosis, their perceptions and expectations for mental health treatment, and their perception of their own role in the child's

treatment. Following the principles of good qualitative interviewing, each interview began with a broad question to elicit a dialogue with the individual (Spradley 1979). Each interview began with "How did your child end up with a diagnosis of ADHD?" This provided a focus for the discussion and allowed participants to express in their own words their personal experiences from when they first noted or became concerned about their child's behaviors up to the time of the initial diagnosis. Additional probing questions included: "What did the doctor tell you that could be done to help your child's behavior?" "How did you feel about medication for your child's behavior?" "What were your expectations for medication?" "How do you believe that the medication would work to help your child?"

Prior to the interview, participant confidentiality was stressed, and permission was obtained to tape record the conversation. Interviews, which ranged from 35 minutes to over 1 hour, were conducted both by the lead investigator and a trained research assistant. All interviews were transcribed. The child's medical charts were reviewed at study entry (baseline) for demographic, family history of psychiatric illness, and initial treatment, as well as at 6 months and 12 months for ongoing treatment. Interviews were also conducted at the 6- and 12-month follow up, and will be the focus of forthcoming papers.

### *Data analysis*

Following grounded theory methods (Glaser 1965), three members of the research team used line-by-line coding to identify parents' initial perceptions of ADHD medication prior to their child's diagnosis or initiation of treatment. Coded text was grouped into thematic categories representing similar meanings. As each new passage was identified, it was compared with other passages assigned to the same code (i.e., constant comparative method) to define the dimensions (i.e., breadth of meaning) of the codes empirically. In this way, the meanings 'emerge' from the data. Weekly discussions were held to assure consensus in the coding and were continued until themes were saturated (i.e., no new information was gained from additional interviews).

The classification of families emerged from the grounded theory analysis. The coded data were displayed in a matrix. This visual display of the data allowed us to look first within each participant to understand their perspective on the basis of how they endorsed each of the constructs from the coded data. This step was critical because each individual's experience was examined to identify their perspective. The coded data within each individual was then compared across participants to identify similar perspectives. Individuals with similar perspectives were grouped together, which reflected patterns in the data that corresponded with the meaning medication held for these parents.

Demographic information and family history of psychiatric illness were also included to provide context for the comparisons. Chi-squared tests were used to assess the association between parental views of medication and continuity of treatment. Significance was set at  $p < 0.05$ .

## Results

### *Characteristics of participants and their children*

Participants were the biological mother (75%), a biological aunt/grandmother (10%), father (8%), or stepparent (7%).

Most were single parents and 88% lived in Baltimore. The highest level of education for most parents was high school.

Children averaged 8.8 years of age (range 6–16 years); 63% were male, 82% were African American, and 64% were enrolled in the state Medical Assistance program. Fifty three percent had co-morbid diagnoses, including adjustment (23%), learning (16%), disruptive (10%), and depression or anxiety (14%) disorders. Nearly half (44%) had a family history of psychiatric illness. One third had a relative with a substance abuse disorder and 23% had a relative with depression. Medication was noted shortly after diagnosis for 84% of children.

### *Constructing the meaning of ADHD medication*

Parents' descriptions of their experiences reflected their initial views of medication for ADHD, before their child was diagnosed with the disorder. This was grounded in how they: (1) Determined what treatment was right for their child (i.e., appropriateness of using medication), (2) evaluated the effects medication would have on their child (i.e., anticipated effect), and (3) assessed the consequences of medication (i.e., the symbolic representation).

It was important for parents to believe it was appropriate to use medication for the problem as they perceived it in their child. Some felt their child was "too young to be put on medication." Parents of younger children questioned whether the behavior was a typical developmental stage, "I would have been ready for medication, but at 5 years old I wasn't sure if that was normal or if it was something more." One father explained it as "an opportunity for things to be better as much as it is an opportunity for things to be worse." Others noted past experiences, "I wasn't worried . . . like I said I have a nephew with ADHD." Some thought "that's how it (referring to medication) was done." Some did not want medication "because I don't think he's that bad to need it." For others it was the right time to try it, "he's getting close to graduating and I need to see what his potential is and he needs to be able to see that he can really achieve things himself." Others restricted use to certain settings, "if I have to give him medication when we go to school it's to see how he works in school." A few parents felt medication was not appropriate because they did not believe ADHD was an illness or thought medication was an addictive substance. One parent said "it's not diabetes or an illness . . . I didn't look at hyperness as being an illness." Another mother stated, "You're going to give me a controlled substance for my 8-year-old son and have me put him on this . . . I disagree with that as a parent."

The anticipated effects for the positive and negative aspects of medication were prominent issues that shaped parents' views. Many parents believed the medication would help their child's academic performance, "that's when she'll start to learn, it'll start to sink in. But without [medicine] I don't think it will sink in." A few hoped the medication was going to help the child to learn appropriate behavior, "once he understands that the medicine is to help him sit down and . . . stay out of trouble and help maintain himself . . . I'm hoping that he can learn to . . . act the same way without the medication." The negative effects were concerns about safety, the risk for addiction and substance abuse, and the possibility that it might change their child's personality. One mother was concerned

about the potential for "suicidal tendencies or . . . growth problems or addictive problems or depression." One aunt caregiver noted "his mother was already a substance abuser so I felt that I couldn't do that to him." Several parents believed that ADHD medication would make their child a 'zombie.' Others believed medication would affect the child's ability to learn, "my little brother . . . he ended up dropping out of school at the 8<sup>th</sup> grade . . . no desire at all to do anything . . . and I blame that on the medicine."

Intrinsic beliefs intersected with social worlds to create a symbolic representation that reflected something different than simply views of the appropriateness or the effects of medication. One parent said, "medication is fine, but you can't always take medicine to fix everything." For others the symbolic connection between medication and a medical condition meant that society would not view their child as 'bad' and that "there's really something wrong." A lower dose comforted one parent because it meant the medication was not "so strong" and therefore the child's illness was not "too bad." One other parent viewed psychiatric medication as something that would "get into their system" or "open up his mind."

### *Integrating meaning of medication with decision-making processes*

Even though 84% of parents initiated medication treatment shortly after diagnosis, on average many had first noted the problem 4 years prior to seeking professional medical advice. Thus, these parental views of ADHD medication before their child was diagnosed helped to better understand what influenced their decisions to use it for their own child. Theoretical dimensions of the appropriateness, effects, and symbolic representation themes are displayed in Table 1. The relationship among the themes mapped into four distinct patterns that reflected how parents viewed ADHD medication: (1) An illness-oriented treatment ( $n = 14$ ); (2) a problem-oriented treatment ( $n = 9$ ); (3) a generally acceptable treatment ( $n = 15$ ); and (4) an unacceptable treatment ( $n = 10$ ). These groups differed on issues that influenced ADHD medication treatment decisions and engagement with medical professionals (Table 2).

Parents who had an illness-oriented view of treatment accepted a medical explanation for their child's condition and believed medication was the medically necessary treatment for the ADHD illness. A key feature of this group was their focus of treatment for a specific diagnosis. Parents relied upon providers for support, guidance, and comfort as they sought medical options. Moreover, providers had a prominent role in making treatment decisions.

Focusing less on ADHD as an illness and more on the challenges in their family's life, parents with a problem-oriented view of medication saw it as a quick remedy to stabilize the behavior. A hallmark feature of this group was their focus on the symptomatic management of their child's problems rather than a specific diagnosis. This allowed them to get on a regular schedule, obtain some relief from the chaos, and maintain respectable behavior. Parents wanted to be involved in the treatment plan for their child, but wanted providers to coach and assist them with implementing effective strategies. These parents formed 'partnerships' with providers and, for some, school personnel as well.

TABLE 1. ATTITUDES ABOUT MEDICATION FOR ADHD ACROSS THEMATIC CATEGORIES THAT DISTINGUISH THE MEDICATION CLASSIFICATION GROUPS

Thematic categories	Medication classification			
	<i>Illness oriented</i>	<i>Problem oriented</i>	<i>Generally acceptable</i>	<i>Unacceptable</i>
Appropriateness	Medication is a medical treatment that is needed for their child's medical condition.	Medication is needed to stabilize/control the behavior, improve school grades, or school performance.	Medication is considered the standard of care.	Medication is a medical treatment but not something that their child needs.
Anticipated effects	Parent is aware of the side effects but still willing to use the medication.	Parent is aware of risks but is willing to use it to correct a specific problem.	Parent is aware of side effects but believes there is more benefit than risk.	Parents believe medication poses more risks than benefits.
Symbolic representation	Medication is seen as a cure; medication proves that child/parents are not bad and there is something medically wrong.	Medication is for short-term use only to avoid future problems.	Medication represents a last hope for relieve and will only be used on a trial basis.	Medication is used by society to control behavior, it is not a regular medicine, and it is only used for severe problems.

Another subgroup viewed medication as a generally acceptable treatment, i.e., it was just "how it was done." Although parents were not necessarily knowledgeable of ADHD or available treatments, they knew that medication was used for childhood behavioral problems. This group did not place their emphasis on a diagnosis or symptom. Rather, they followed what they viewed as 'typical' treatment for ADHD. Parents discussed using medication on a "trial basis" to see that it worked before they deemed it appropriate. Others simply described "going with the flow." Several believed that treatment now would prevent the need for medication in the future. Parents relied on the clinician to educate them, "what's the next step for me to take . . . what [do] I need to do to handle him with his ADHD."

Those who viewed medication as an unacceptable treatment were skeptical of medication and felt the situation could be managed without it. As one mother expressed, "medication was everyone's answer to everything . . . this can't just be the end all and be all. There has to be other answers." One

father explained that there was no need for medicine because "my understanding [is that] the medication is basically to control him." These parents were the primary decision maker for the care of their children, and providers played a minimal role; they were just one of many sources of information.

#### *Meaning of medication and its relation to treatment continuity*

Medication use for the child varied across the different meaning of medication classification groups (Table 3). The difference was statistically significant at baseline ( $p < 0.0001$ ), but not at 12 months. This should be interpreted with caution given the small numbers. Aside from one parent, who was still gaining a comfort level with the prospect of medication, all those who viewed medication as an illness-oriented treatment had initiated stimulant treatment shortly after receipt of the diagnosis. All of the parents with a problem-oriented or a generally acceptable view had initiated stimulant treatment

TABLE 2. DIFFERENTIATION AMONG MEDICATION CLASSIFICATION GROUPS IN RELATION TO TREATMENT DECISIONS AND PROVIDER ALLIANCES

Medication classification group	Treatment decision	Clinician alliance
Illness oriented	Adopt the standard of care	Seeks medical options, comfort, and guidance from clinicians
Problem oriented	Regain stability Enable child to succeed	Clinician informs and educates, parents partner with clinicians as experts in the care of their child, but medication is the primary focus
Generally acceptable	Follow recommendations and realize that medication is part of the process	Relies on the clinician for education and guidance but parents are the advocates
Unacceptable	Search for alternative treatments	Parent maintains skepticism about medication and clinician is part of the information gathering process

TABLE 3. TREATMENT ADHERENCE ACROSS THE FOUR MEDICATION CLASSIFICATION GROUPS

Medication classification group	n	Baseline <sup>a</sup> n (%)	6 Months <sup>b</sup> n (%)	12 Months <sup>c</sup> n (%)
Illness oriented	14	13 (93)	12 (86)	9 (64)
Problem oriented	9	9 (100)	9 (100)	7 (78)
Generally acceptable	15	15 (100)	10 (67)	5 (33)
Unacceptable	10	3 (30)	5 (50)	4 (40)

<sup>a</sup> $p < 0.0001$ .<sup>b</sup> $p = 0.052$ .<sup>c</sup> $p = 0.12$ .

shortly after their child was diagnosed with ADHD. Despite strong feelings against medication before their child was diagnosed, 3 of the 10 parents who viewed medication as unacceptable had decided to use it. Medication use was discontinued by the majority of children whose parents viewed it as a generally acceptable treatment, and most of the parents in the unacceptable treatment group never used medication for their child. About 25% and 33% of children whose parents viewed medication as a problem- or illness-oriented treatment, respectively, had discontinued treatment by 12 months.

Of the 48 parents in this study, 14 (29%) had stopped getting services at the clinic and 7 (15%) had dropped out of the study. The percentage within each group that was lost to follow up was 21% ( $n = 3/14$ ) in the illness-oriented group, 11% ( $n = 1/9$ ) in the problem-oriented, 40% ( $n = 6/15$ ) in the generally acceptable, and 40% ( $n = 4/10$ ) in the unacceptable group.

## Discussion

Parents' decisions to treat their child for ADHD emerged from opinions about when medication is the appropriate treatment, expectations about the medication effects, and evaluation about what medication use represents. In this primarily minority, inner-city sample, 29% felt that medication was necessary and 20% viewed medication as an unacceptable treatment. On average, parents had first noted their child's problems 4 years prior to obtaining the diagnosis. It may be that by the time they sought medical advice they were more open to medication. This may explain the high proportion of parents that initiated medication shortly after diagnosis. The extent to which attrition is due to lack of effectiveness relative to parental expectations warrants further study.

These findings corroborate parental views of ADHD as a medical problem, a general illness, or not a problem requiring medical intervention (Mychailyszyn et al. 2008) as well as other qualitative research on care-seeking for their child's ADHD (dosReis et al. 2007; Leslie et al. 2007). Other researchers have similarly reported high medication discontinuation rates over a 1-year period (Marcus et al. 2005). However, prior findings about the concerns with medication (Schnittker et al. 2000; McLeod et al. 2004) and hesitancy to use stimulants (dosReis et al. 2003; McLeod et al. 2004; dos-

Reis et al. 2006) do not reflect how parents weigh the risks relative to the potential for improvement when deciding to use medication for their child. This study provides a conceptual foundation for such views and offers important implications for ADHD treatment in clinical practice settings.

The relevance to clinical care may be better identification of barriers to parents' willingness to use a first-line ADHD medication for their child. Parents who specifically seek medication to solve the problem may start treatment and continue using it, assuming they see improvement. One could hypothesize that partial or no improvement may discourage ongoing involvement in care, and so discussing treatment response, both initially and throughout the course of treatment, may be crucial. Parents who believe that continuous medication use is necessary to remedy the ADHD symptoms may readily engage and remain compliant despite acute exacerbations or partial response. The clinician can work within the context of knowing that these families will withstand some fluctuation with treatment. Views that medication is unacceptable pose a greater challenge, especially given that stimulants are first-line treatment for ADHD. It appears that this group is a minority and cannot account for the reported poor adherence to stimulants (Marcus et al. 2005).

The findings also are applicable to enhancing parental involvement in treatment. Treatment plans that are tailored to parental perspectives increase the child- and family-centeredness of care (Johnston et al. 2005). In addition, clinicians may gauge what intervention is best and when to implement it (Aikens et al. 2008). In this study, illness-oriented, problem-oriented, or generally acceptable treatment groups were more open to the prospect of medication from the start, and nearly all had initiated medication treatment for their child. There is likely to be some resistance by parents who are unfamiliar with medication or who initially do not feel that this is what their child needs. If addressing these issues early keeps parents engaged in care despite feelings of uncertainty throughout their decision-making process, this may improve treatment effectiveness and child outcomes. An important next step for this research is to help providers identify parental views during the initial contacts so they may engage families sooner.

Understanding parents' view of the problem, the rapidity with which they accept medication treatment, and the perceptions of medication provide a wealth of information that may help providers better connect with the families and children they treat for ADHD. Parental views may affect therapeutic alliances between parents and pediatric providers, as illustrated in a conceptual model of parental involvement in treatment (dosReis and Myers 2008). Other researchers have reported that dissatisfaction with care was related to negative impressions of the communication with clinicians (Concannon and Tang 2005).

Knowledge of parents' expectations may impact education and guidance through different treatment options, both initially and in ongoing care. For example, parents who viewed medication as a generally acceptable treatment had expressed its use as a 'trial basis.' Treatment discontinuation in this group may have been due to parents' expectations for a better treatment response relative to what they were observing in their child. Also, medication use among children of parents who viewed the medication as unacceptable remained relatively low, indicating that these parental views had not

changed. From a clinical perspective, the medication classification groups may help providers predict which parents would be more likely to discontinue medication over the course of treatment. Important next steps are to identify the circumstances that lead parents to stop medication treatment or to lose contact with the clinic. This knowledge would inform interventions that could be used to minimize treatment discontinuation.

The findings should be viewed within the context of several limitations. First, the views of parents who seek care for their child's behavioral problems may differ from those who do not, and this study may underestimate the proportion that views ADHD medication as an unacceptable treatment. Second, we did not assess how attitudes may change and evolve with experience and clinical interactions. Future longitudinal studies based on this framework are forthcoming. Third, data may be missing if treatment was obtained from a clinic that was not part of the study. However, 94% of children had medical insurance, which does not pay for duplicate services, and so it is unlikely that they obtained care outside of the study site. It is possible, however, that families who had stopped bringing their child to the clinic may have obtained care elsewhere, and for these individuals data would be missing. This may have affected the 14 (29%) individuals who were no longer in contact with the clinic at 12 months. Fourth, it was not possible to determine if side effects or lack of response influenced parental decisions to continue medication treatment. This information was not systematically available in the medical charts across the study sites. As part of this study, follow-up interviews were conducted with parents, and these data will be reviewed to identify what led parents to stop medication treatment. The purpose of the present study was to identify perspectives of treatment before the child was diagnosed with ADHD or started on medication. This baseline information will be used in forthcoming analyses that will examine adherence. This issue is complex and important enough to warrant a separate paper. Finally, it was not possible to compare parental perspectives across socioeconomic groups or in suburban settings where psychosocial stressors, which may influence views, are presumably less prevalent. Even so the findings are useful because the study sample represents those families most hesitant to use ADHD medication and most vulnerable to discontinue treatment.

## Conclusion

This study suggests that identifying parental attitudes about their child's ADHD and its treatments that may lead to noncompliance is likely to produce clinically relevant information about the parents' understanding of the disorder and the need for treatment. This can help providers create opportunities to engage parents in treatment decision making early on in therapy. The extent to which decisions regarding medication choice, dosage, trials, or weekend/summer holidays reflect parents' preferences will influence how well the medication regimen is accepted and maintained. Hopefully, the expanding body of knowledge about parental views and preferences for using medication for their children will foster change in medical practices that ultimately improve outcomes for children and adolescents. This investigative team is pursuing research to help clinicians identify parental views effi-

ciently and validly to implement treatment plans that parents are comfortable with and likely to maintain.

## Disclosures

Drs. dosReis, Evans-Lacko Riley, and Myers and Mr. Mychailyszyn, and Ms. Beltran have no financial ties or conflicts of interest to disclose.

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