

# Using Stimulant Medication for Children with ADHD: What Do Parents Say? A Brief Report

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## Abstract

**Introduction:** Long-term adherence to stimulant treatment for Attention Deficit Hyperactivity Disorder (ADHD) is frequently poor. Since parents are the key decision makers regarding their child's health care, their thoughts regarding medication use are crucial to whether children take prescribed stimulants. To develop an understanding of what parents think about using stimulants to treat their children's ADHD symptoms we consulted groups of parents about their experiences. **Methods:** Using qualitative methods informed by phenomenology, three focus groups of parents were asked to describe their experiences parenting a child with ADHD and using stimulant medications for treatment. Participants were 17 mothers and fathers of 14 children with ADHD, ages 7-14 years, who had received detailed diagnostic assessments and had used stimulants. Focus group dialogue was recorded and transcribed. Using established methods of data analysis, themes were identified and explored. **Results:** Accepting that one's child has ADHD and needs treatment is a difficult and lengthy process, often accompanied by confusion and self-doubt. Parents find the choice to use stimulant treatment particularly challenging given the conflicting opinions they hear from family, friends and professionals. **Conclusions:** Universally, parents want to do what is best for their child. Adverse effects, concerns about stigmatization, and the child's dislike of taking pills, all contribute to parents' decisions to discontinue medication even when the child shows symptomatic benefit.

**Key words:** attention deficit/hyperactivity disorder, psychostimulants, treatment adherence

## Résumé

**Introduction:** On dispose de peu de données sur l'utilisation à long terme de psychostimulants dans le traitement du déficit d'attention avec hyperactivité (TDAH). Dans la mesure où ce sont surtout les parents qui décident des soins donnés à leurs enfants, leur opinion sur les médicaments est essentielle si l'on veut que les enfants prennent les stimulants qui leur ont été prescrits. Souhaitant savoir ce que les parents pensaient des stimulants dans le traitement du TDAH chez leur enfant, nous avons demandé à différents groupes de parents de nous faire part de leur expérience. **Méthode:** Nous avons utilisé des méthodes qualitatives qui font appel à la phénoménologie. Les parents d'enfants qui souffrent de TDAH et sont soignés par stimulants ont été répartis en trois groupes cibles. Dix-sept pères et mères de 14 enfants souffrant de TDAH âgés de 7 à 14 ans ont participé à cette étude. Les enfants avaient fait l'objet d'une évaluation diagnostique détaillée et prenaient des stimulants. Le dialogue des groupes cibles a été enregistré et transcrit. Les thèmes ont été définis et analysés au moyen de méthodes éprouvées d'analyse de données. **Résultats:** Les parents ont de la difficulté à admettre que leur enfant souffre de TDAH et doit être soigné. Les thèmes qui reviennent sont l'évaluation approfondie et les problèmes à l'école. **Conclusion:** Tous les parents veulent ce qu'il y a de mieux pour leur enfant. Les effets secondaires, le fait que les enfants n'aiment pas prendre de pilules et la stigmatisation sont les facteurs qui expliquent pourquoi les parents décident d'interrompre le traitement même lorsqu'il est évident que l'état de l'enfant s'améliore.

**Mots-clés:** déficit d'attention avec hyperactivité, psychostimulants, respect du traitement.

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## Introduction

Stimulant medications, such as methylphenidate, reduce the inattentive, overactive, and impulsive behaviors that characterize children who have attention deficit hyperactivity disorder (ADHD) (Jadad et al., 1999). Despite evidence of efficacy, many children who try medications stop taking them. Rates of adherence to stimulants vary from 25% to 50% 12 months after starting medication (Corkum, Rimer, & Schachar, 1999; Kent, Camfield,

& Camfield, 1999; Schachar, Tannock, Cunningham, & Corkum, 1997). Baseline predictors of continuous use of medications over three years are: younger age at diagnosis, severity of ADHD symptoms, and lack of oppositional defiant disorder (Thiruchelvam, Charach, & Schachar, 2001). Adverse effects, are most frequently cited as the reason for discontinuing treatment in the first few weeks to months of use (Schachar et al., 1997), but some children continue to use medication for

up to five years even while experiencing side effects (Charach, Ickowicz, & Schachar, 2004). Clearly other factors in addition to adverse effects contribute to decisions about long-term medication use for children with ADHD.

Families of children with ADHD go through a series of steps prior to accepting treatment - they identify that the child has a problem, they seek an evaluation, and they receive a diagnosis which they may or may not accept (Bussing, Mason, Leon, & Sinha, 2003; Bussing, Zima, Gary, & Garvan, 2003). Many parents believe that diet affects hyperactivity, are hesitant to use medication because of media reports, or simply are reluctant to see their child as having a medical problem (Bussing et al., 2003; Dosreis et al., 2003; Singh, 2003). Families find behavior therapies more socially acceptable than medication (Liu, Robin, Brenner, & Eastman, 1991). Many describe negative comments from friends and family and worries that taking medication may stigmatize the child (Bussing & Gary, 2001). Not surprisingly, parental beliefs about etiology of ADHD behaviors in children are associated with treatment choices (Johnston, Seipp, Hommersen, Hoza, & Fine, 2005). Among a group of Latina mothers, inadequate adherence to stimulants for their young children was consistent with beliefs that medication could be addictive, dull cognition and was inappropriate for behavior problems (Arcia, Fernandez, & Jaquez, 2004). Parents are more accepting of stimulants for their children when the diagnostic process has been thorough, including comprehensive psychological testing (Bussing & Gary, 2001). Choices about medications can change over time, with schools and extended family members influencing parental decisions (Arcia et al., 2004).

Several psychological models of behavior have been proposed to explain treatment adherence. The health belief model, first proposed in 1970s, has been used by several authors to explain medication adherence in psychotic patients (Bebbington, 1995; Corrigan, 2002; Perkins, 1999). The model has been elaborated to include the impact of social influences and intentionality, and the context of patient-provider interactions (Burkman, 1999; Mahone, 2004; Ried & Christensen, 1989; Ryan, 1999; van Es et al., 2002). The role of

habit has also been introduced as a salient feature that can promote long term adherence to medical treatments (Reach, 1999). Aspects of these health decision models have been tested and found to have some explanatory merit in patients with diabetes, asthma, urinary tract infections, and epilepsy (Bond, Aiken, & Somerville, 1992; Jessop & Rutter, 2003; Ried & Christensen, 1989; Shope, 1988; van Es et al., 2002). None of these models has been applied to children's mental health disorders.

Parents are key decision-makers regarding their children's health care. Therefore their views regarding stimulant medication use are crucial to whether children with ADHD use stimulant medication. To understand the factors that influence adherence to stimulants from the perspective of parents we asked small groups of parents whose children have ADHD and who had tried stimulants to describe their experiences. The goal was to investigate how parents think and feel about stimulant treatment for their children using a phenomenological approach.

### **Methods:**

*Sample:* A sample of 17 parents of children with ADHD were recruited by a known health care professional to participate. Parents were identified through their children. The children were selected sequentially from a list of patients who had participated in systematic diagnostic assessments over a one-year period at a specialty clinic for children with attention, learning and behavior disorders at The Hospital for Sick Children, Toronto, Ontario. Inclusion criteria for children were diagnosis of ADHD by Diagnostic and Statistical Manual, Fourth edition, (DSM IV) (APA, 1994), criteria (any subtype), age 6 -12 at time of assessment, previous use of stimulant medication, and parents able to communicate in English. Children who had other medical, developmental or psychiatric conditions that required ongoing medical treatment were excluded. The 14 children, 3 girls and 11 boys, ranged in age from 7 to 15 years at the time of the parent focus group; seven children were taking medication and seven were not. Sampling continued until data analysis revealed that saturation of major themes had been reached, consistent with the qualitative method underpinning this study.

Consistent with other research in chronic illness, and the clinical experiences of this team, the majority of participants, 13 of 17, were mothers. Two of the mothers were single parents, three families came as couples, one of these was divorced but co-parenting. Parents ranged in age from 34 to 50 years, 16 were Caucasian, 16 were high school graduates, 11 had completed college or university, 13 were employed outside the home, and 1 received social assistance.

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*Data collection:* A venue outside the hospital and geographically convenient to the families was chosen for each of the groups in order

to provide a more neutral environment and to support authentic expression of views. A social worker and practical nurse specialist, both familiar with working with families of children with ADHD led the 3 focus groups. They were audio-taped and transcribed verbatim. Notes were taken at the time of the groups as well, to document dominant and minor themes. Using a semi-structured guide, parents were asked to describe their experiences living with and parenting a child with ADHD. In particular parents were asked to describe their experiences regarding use of medication for the child's symptoms.

Data analysis was consistent with recognized methods in the qualitative field (Patton, 2002; Strauss and Corbin, 1990). First, each transcript was read line by line to code key words and phrases relevant to the research questions (free coding). Second, the coding process was reviewed with the interdisciplinary research team to enhance the authenticity of codes chosen. The team deliberated on the special challenges that focus group data present for the researcher (Smithson, 2000) (Vaughn, Schumm, & Sinagub, 1996) and reviewed the coding process in light of the context of the focus group dynamics. As thematic analysis continued, dominant voices in a group were noted, allowing for active recognition and identification of minority themes as well as dominant ones. Finally, codes were clustered so that key themes were established that best represented a number of the free codes (axial coding).

The protocol was approved by the Research Ethics Board of the Hospital for Sick Children. To evaluate reliability of findings participating families were sent a summary of the results and asked to provide their opinion regarding the accuracy of the findings. In addition, the results were shared with a group of 16 clinicians with experience working with ADHD children and their families to obtain their impressions of the validity and transferability of the results. These member checking methods are an important component of establishing rigor in qualitative studies.

### **Results:**

Parents described a range of experiences about living with a child who has ADHD. They

shared with us a variety of paths leading to assessment and diagnosis and to the choice of using stimulant medication. They also described that the initial decision is only one in a series of decisions regarding medication use. Prominent themes were 1) an experience of confusion and feeling blamed or responsible for the child's behavior, 2) the need for time to digest and reflect upon information about their child's difficulties and to consider treatment options, and 3) a strong desire to do what is best for the child, balancing treatment benefits against concerns about safety, stigmatization and respect for the child's wishes.

### **What parents said about receiving a diagnosis of ADHD for their child:**

Parents told us that discovering a child has ADHD is difficult. Our parents expressed both the delight and challenge of raising a child with ADHD. The children were described as "bubbly," "very social," as having "great personality," and "bright." The challenging side was revealed in statements like "I needed to learn how to ignore the negative behavior," "I need to pick my battles," "It's a constant struggle" and "It's challenging and tiring." For many, the process of seeking assistance, receiving a diagnosis, and accepting the label of attention deficit disorder was complex and difficult.

Almost all parents mentioned that, in general, people in their social circle do not understand ADHD. Extended family, friends and neighbors often view children with ADHD as misbehaving and consequently blame parents for poor parenting practices "insinuating that we let him do what he wants and that is why he is like that". Another view expressed was "There's a belief system out there that it is more of a behavioral issue." One parent had noticed at a hockey game "how the other parents react...by attacking the kid who's not behaving well because he is not brought up right". Alternatively, parents hear reassurance that the difficulties their child is experiencing are normal – "He'll outgrow it." Often the problem behaviors became more clearly identified when the child entered school and had difficulty learning, staying on task and managing in the classroom environment.

Parents also described searching for answers and often having trouble accepting the

diagnosis of ADHD. The following views were typical: "We went for all this testing to find out if it is this, if it is that." "I went through a lot of reading, and parenting courses to understand why my kid is different from other kids." One mother described the process as moving from experiencing her child as "perfect" to..."There is something wrong"...to..."What do you mean he has ADHD?," because of course you don't want to hear these things." One mother noted that "when they (the teachers) told me 'there was something seriously wrong with your child,' I thought, 'well, you are not a good teacher.'" More than one family recalled feeling responsible for their children's problems. "You go through the guilt of what did I do? Did I do this?" One mother reviewed her habits during pregnancy: "I didn't smoke, I didn't drink, I didn't gain a lot of weight...You kind of feel guilty, maybe it was that drink I had at Christmas."

Parents also described needing time to digest the information that the child has ADHD and may need to take stimulants. Several complained about overly brief assessments, and what appeared to be hasty decisions by doctors to offer medication. "I wasn't happy about this short questionnaire one day, and medication two days later." All of the families who participated needed a period of time to consider their options. Many described a change in attitude and acceptance of the diagnosis. "That period of three to six months...the words were used and you sort of come to terms with the diagnosis...and then...what do you do about it?" "Three years of testing - I think one just has to process the information." "There is a 'Before' and an 'After' in terms of understanding of ADHD." Parents received conflicting opinions and advice from lay and professional, formal and informal sources throughout the process leading to referral and assessment. Receiving the diagnosis of Attention Deficit Hyperactivity Disorder did not always relieve the confusion. Many needed time to accept the diagnosis.

### **What parents said about the decision to use stimulant medication treatment:**

Deciding to try medication was difficult for most. Several reasons contributed. First, parents continued to feel responsible for the child's problems - "like you failed somehow and

you are giving your kid medication." Second, many had fears about the safety of medication. "We were scared because we heard about... filling up kids with drugs and they are zombies." In considering pills for the child many preferred to try something else first. One mother recalled asking, "Is there any other way? Is there an alternative?" Another mother stated, "I didn't want to put drugs into my child's body I wondered if there was any other way." After doing her own research, another decided the case for using medication "was sort of like yes, there were some cases that were unbelievable (excellent results) but there were other cases that weren't so positive". Another family described the process, "So we started the Ritalin, not knowing if it was the right thing or not, but figuring we had tried everything else." Once they had come to a decision to try medication treatment, accepting a trial of stimulants was easier. Most felt that a trial of medication "can't hurt for a month."

A third reason the decision to use medication was difficult involved family, friends and other influential people not understanding the issues or actually supporting a trial of medication. Participants spent a lot of time discussing conflicts with grandparents and other extended family members. One mother was told by her husband's brother, "Don't you go to those doctors, don't you listen to them, don't you ever put your son on medicine." Another mother reported, "we have family who don't agree with our decisions...It makes things really tough." Yet another recalled, "My mom was always like, 'Do you have to put him on something that will take away that personality?'" Further, spouses could not always agree with each other: "You are like 'let's just try this, let's try anything,'....I was pushing my wife on it."

Our parents also experienced mixed responses from school professionals. Sometimes, teachers were supportive of medication use, as in "he has many teachers say...you are denying him the potential that he actually has got (by not using pills)." But other educators were against using medication. "The school was really pushing for non-medication therapy." One mother had heard from a principal, "Well, my son is 30 and he never had medication and he is a success." Conflicting opin-

ions added to confusion about what to do. One parent noted that handling the responses of other people was a real challenge in deciding to use medication.

Negative media portrayals of medication use also complicated the decisions for parents. "If you are in the situation where you are forced to use the medication you can't help but feel the guilt because they (media) are presenting that image...putting kids on medication because it is easy." Another recalled a recent print article: "On the cover of (a popular) magazine, 'Are we over-medicating our kids?'" Parents described feeling that "you tell people you are giving your child drugs and they think there is something wrong with you." The media portrays that "it is convenient to pop a pill" adding to the blame parents experience from others and the guilt they feel themselves.

Parents also emphasized the importance of educating those around their children about ADHD so they could feel more supported. Attempting to provide that education themselves, however, was seen as problematic because of the ever-present fear of negative repercussions to the label of ADHD. Parents frequently experienced stigma associated with having a child with ADHD. "In the beginning... I didn't want him labelled, I didn't want him to stand out." One mother acknowledged avoiding a team activity for her son because when people don't understand his ADHD "it was easier just to stay home on Tuesday nights."

The decision to use or not to use medication was an ongoing process for many parents. Several families noted that they still continue to search for additional ways to assist their child beyond the help medication provides. In addition to using medication parents work to find school programs and extracurricular activities that match the child's needs. Many families have focused on providing a healthy diet. "We realize it is...a combination of things" that can be helpful. Some parents have looked for school programs that are small and nurturing, some have offered their child food additives, while several avoid excess sugar. They have tried new parenting techniques, organizational aids, and new methods for teaching skills to their children including neural feedback and "brain gym."

### **An important theme for parents was the question "What is best for my child?"**

Most parents viewed their decision as one of balancing the costs of using medications against the benefits. The gravest concerns expressed were that a child might experience adverse physical effects and be stigmatized because of using medication. An important aspect of the ongoing decision process was the willingness of the child to take the medication. The following examples illuminate how parents described their decisions regarding stimulant medication. Some families used medication even though a child experienced adverse effects because the results, especially in school, were very positive. One mother noted "he has a twitch in the eye and is very thin but is getting good grades and doesn't cry...a miracle for the crying and the anxiety." A second mother reported "he suddenly could focus, he is doing well...It makes our decision very, very easy whether to medicate or not." Over and over again parents expressed the desire to make the best choices for their child. They underlined that it is important to make "the right choice for you at the right time and for the child..." They wanted to do "what's best for the child." Another mother described for the group how she had told herself "I am going to do what is right for my son. I am not going to think of them" in the face of strong opposition from extended family. The same evaluations of costs and benefits were made by parents whose children were not on medication. "He was more organized but he could not sleep, hardly ate anything...he had *that look*. If it had been different, we might have kept him on it." Another reported "we could never regulate it properly...it quieted him down but he got like a zombie." The process of evaluating what was best for the child with ADHD didn't stop after a few weeks of trying medication. The decision was not always clear cut and needed to be revisited repeatedly.

Four of the 7 children not on medication had experienced adverse effects leading to discontinuing the pills. These included a widespread rash, becoming lethargic, insomnia, poor appetite, stomachache, feeling itchy and facial tics. Another adverse effect was described as a "loss of personality." One parent described that on medication her young-

ster became "no longer my child." Four of the 7 children didn't want to take the pills. One child regularly spit out the pills, felt unable to swallow them, complained of stomachaches, and constantly fought about taking the pills. A second child (age 14 at time of focus groups) had had several adverse effects, including insomnia, poor appetite, and a "glazed look" for several years, then at age 12, he said he felt high and didn't want to take the pills. At the time he was receiving the "Say 'no' to drugs" message at school, and chose to say "no" to stimulants. His parents agreed to his request. The third child (age 12 at time of focus group) was very quiet at school, like a "zombie" and said he didn't want to take the pills. The fourth child had had daily fights to avoid taking pills, at age 8 years had "acted stoned" and said the pills made him feel terrible, and at the time of the focus group (age 11 years) was unwilling to try any medication again. Two children had reported to their parents that other children teased them about taking pills at school. "Kids would say 'go and take your *stupid pills*.'" More than one mother worried that the label of ADHD might be damaging to her child's self esteem.

The ongoing discussion of what was best for their children was particularly poignant for those fathers and mothers who had experienced similar difficulties with cognitive organization and memory when they were young. "We...learned through our lives taking the lumps, whereas today maybe we run to the rescue too quickly." Another father wondered, "Are we babying our kids by giving them all these cushions and helping them follow through?" Or by using stimulants, are we "denying him the potential benefits?" of not using the medication. For these parents a potential cost was that taking away the challenging symptoms might make life too easy for their children. However, one of these fathers clearly had mixed feelings, he also said, "I am not against it...Whatever helps do it," referring to using stimulant medication. Overall, for those parents whose children clearly benefited from medication and accepted taking it, parents found the decision to use stimulants relatively easy. For many participants, however, using stimulant medication remained a poor option.

Credibility of the results is supported by

feedback from checking with members of the focus groups and with a group of experienced clinicians. We received feedback from three of the 14 families who told us they agreed with the summary report of what was said in the groups. Feedback from clinicians confirmed that many families have reported similar thoughts, ideas and experiences about using stimulant medication for children with ADHD. When discussing transferability, however, one clinician pointed out that parents from less advantaged circumstances than these participants might have described additional financial and instrumental barriers to using medication.

### **Discussion:**

For health care professionals a decision to use stimulant medication for a child who is inattentive, hyperactive and impulsive may appear simple, but to parents it is not. What parents reported here offers a complex view of the issues around the use of stimulant medication for children with ADHD. They experience confusion, feel blamed or guilty about their children's behavior problems and need time to adjust to the idea that their son or daughter has Attention Deficit Hyperactivity Disorder and to the idea that the best treatment is stimulant medication. Confusion results in part from the multiple conflicting messages received from relatives, friends, educators, professionals and the media. Contributing to the confusion are experiences of self-doubt about parenting skills compounded by subtle and not-so-subtle messages from others blaming parents for a child's poor behaviours. Our findings support earlier reports that parents hear negative comments from family and friends, are worried about stigmatization, and can be influenced by media reports (Bussing and Gary 2001, Bussing et al., 2003; Dosreis et al., 2003; Singh, 2003). Such factors all contribute to a parent's reluctance to accept a diagnosis of ADHD followed by treatment with stimulant medication.

Prior to reaching a decision about treatment our parents experienced a multi-step process. Initially, they had to ask "what is wrong with my child?," followed by a search for answers to this question, including the diagnostic assessment. The next step was to search for solutions to the child's difficulties. Many families preferred to find alternatives to

medication. This group of families did choose to try medication, however many, although not all, of these parents are Caucasian and come from relatively affluent backgrounds with some college level education. Understanding ADHD as a medical illness and accepting medication treatment is more common among well educated, affluent and Caucasian families, and among mothers rather than fathers (Bussing, Gary, Mills, & Garvan, 2003; Bussing, Koro-Ljungberg, Gary, Mason, & Garvan, 2005; Singh 2003). Parents from less affluent or minority ethnic backgrounds might not find the choice of a medication trial so easy.

All parents expressed the desire to do what is best for their child. Families balanced the costs and the benefits of using medication, like they balanced the costs and benefits of many other decisions made for their children. Experiencing adverse effects, the child's dislike of taking the pills, and concerns about the impact of stigmatization on the child's self esteem all contributed to decisions to discontinue medication even when the child showed clear symptomatic benefit. Balancing the risks and benefits of treatment fits the health belief model of treatment adherence. This model has recently been used to explicate medication adherence issues for severe mental health conditions like psychosis (Corrigan, 2002; Perkins, 1999). However the health belief model describes an adult approach to medical decisions and does not accommodate the bidirectional relationship between parent as decision-maker and child as patient. Several of our parents described revisiting the decision about medication use on a number of occasions over several years. Especially when children object to taking medication, parents may be more likely to accept their child's preferences as they enter adolescence. We know from earlier work that the process of adherence to stimulants is an ongoing one, as many children stop and restart medication over several years following initial use (Charach et al, 2004).

To our knowledge this is the first systematic description of the views parents have about the treatment choices they must make regarding stimulant medication use for their children with ADHD after the child has started taking medication. Limitations to the study include the fairly small number of informants who were needed

to reach saturation of themes and its effect on transferability of the results. The transferability of our findings is supported, however, by our checking with members of the groups and by our consultation with experienced clinicians who had met numerous families with similar issues around the use of stimulants for their children. The clinical implications of our findings are that health care professionals who work with children with ADHD and their families must remember that adherence to medication is an ongoing and evolving process. Parents re-evaluate their decisions about medication at many time points in their child's development. Clinicians should offer regular opportunities for open discussion of both parent and child concerns, reviewing together public stereotypes and misconceptions about ADHD and stimulant use in young people.

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