

# Parental Knowledge of Attention-Deficit Hyperactivity Disorder and Opinions of Treatment Options: Impact on Enrolment and Adherence to a 12-Month Treatment Trial

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*Objective:* This study examines the relationship between parents' knowledge of attention-deficit hyperactivity disorder (ADHD) and opinions of treatment and their impact on enrolment in and adherence to both pharmacological and nonpharmacological interventions for children with ADHD.

*Method:* Participants in the study were the parents of 81 children who reached diagnostic criteria for ADHD and who were referred to a treatment study of ADHD involving stimulant medication and parent groups. The mothers completed a modified version of the ADHD Knowledge and Opinion Scale (AKOS) prior to receiving diagnostic feedback and prior to the families' decisions to participate in a 12-month randomized trial (medication [methylphenidate or placebo] and parent groups [training or support]). Treatment enrolment and adherence were monitored over the 12-month trial, and families who remained in the study at 12 months completed another modified AKOS.

*Results:* A higher level of knowledge of ADHD was found to be related to more favourable opinions of parent groups but not of medication. Moreover, parents who were more knowledgeable about ADHD were more likely to enrol in both pharmacological and nonpharmacological treatments. Adherence to pharmacological and nonpharmacological treatments was not predicted by parental knowledge of ADHD or opinions of the treatment.

*Conclusion:* Parents' knowledge of ADHD and opinions of treatments play a significant role in enrolment in treatments for their children with ADHD. Providing information to parents regarding ADHD prior to offering treatment modalities could have a favourable impact on treatment enrolment and hence treatment adherence.

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**Key Words:** attention-deficit hyperactivity disorder, treatment adherence, treatment acceptability

Attention-deficit hyperactivity disorder (ADHD) is the most common problem presented to children's mental health services (1). It is estimated that 5% to 10% of all elementary school-age children are diagnosed as having ADHD (2). Treatment of ADHD primarily consists of stimulant medication and behavioural interventions used in isolation or in

combination with one another. For example, Wolraich and colleagues found that 80% of children with ADHD were treated with stimulant medication (3). As well, systematic nonpharmacological interventions (for example, parent-training courses, family therapy, behavioural-management training) were found to be recommended with less frequency than was medication.

Long-term outcome for children with ADHD appears to be correlated with the length of adherence to treatment (4); however, many families do not enrol in recommended treatments or do not adhere to the treatment for the entire duration. In a study that examined adherence in families with a child with ADHD receiving methylphenidate (MPH) alone, MPH with a behavioural program, or placebo with a behavioural program, 20% of children had discontinued medication by 4 months, 45% had discontinued by 10 months, and 51% of the families did not follow the behavioural intervention program to completion (5).

Lack of adherence to treatments for ADHD is not explained by factors such as socioeconomic status, parenting stress, or

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family coping style (6). Alternative explanations for treatment compliance may revolve around parents' knowledge of ADHD and their opinions regarding treatment. To date, few studies have explored alternative explanations for enrolling in and adhering to recommended treatments (for example, 6–8). The majority of studies employ analogue methodology (for example, case vignette), and a few employ nonrandomized clinical trials to assess how knowledge and opinions impact on acceptability ratings of various treatments. Generally, nonpharmacological interventions were rated as more acceptable than medication, knowledge of ADHD correlated with the acceptability of interventions, and stimulant medication was viewed more favourably after exposure to treatment.

This study evaluates parents' knowledge of ADHD and opinions of treatments prior to families being randomized to a 12-month treatment study that included medication (MPH or placebo) and parent groups (parent training or support). All children had been rigorously diagnosed with pervasive ADHD and were medication naive. This allowed us to examine the relationship between knowledge and opinions as well as their impact on enrolment in and adherence to both pharmacological and nonpharmacological interventions. This study is unique in that it differentiates between enrolment and adherence and examines real-life adherence to treatments over an extended time frame.

## Method

### Subjects

The sample comprised 81 families referred to an extended treatment study of ADHD at the Hospital for Sick Children (Toronto, Ontario) who had a child who reached criteria for ADHD (9). The study was approved by the institutional ethics board, and both parental consent and child assent were obtained. All 81 children had a confirmed diagnosis of ADHD. The children ranged in age from 5 to 12 years and comprised 70 males and 11 females. Of the 81 families, 69 agreed to be randomized to receive either MPH or placebo for their child, in conjunction with a parent-training or parent support group. (For details about the randomization process, see Schachar and others [9].) The remaining 12 families opted not to participate in the extended treatment study.

Families were excluded from the study if the child had a full-scale IQ score less than 80, suffered from a chronic medical condition, was enrolled in a full-time residential or day treatment program, or presented with ADHD symptoms that were determined to be secondary to a primary affective or anxiety disorder. Families were also excluded if the parent could not communicate in English.

Family characteristics were determined based on information provided on the "Family and Household Form" (2). The mothers' mean age was 37 years ( $SD = 5.6$  years). The majority of families were "blue-collar workers" (65.2%), with a smaller proportion of "white-collar workers" (17.5%) and unemployed families (17.3%). Single parents constituted

30.9% of the sample. The range of education of mothers included having completed elementary school or some high school (17.3%); having completed high school (22.2%); having had at least some post-secondary education (60.5%). Approximately one-quarter of the mothers reported having been treated for "nerves" in the past (23.5%).

### Diagnostic Measures

A rigorous clinical diagnostic assessment was conducted for each child. Diagnostic evaluation consisted of a face-to-face parent interview, a telephone interview with the child's teacher, and a comprehensive child assessment. The parent interview (Parent Interview for Child Symptoms [PICS]; Schachar and Wachsmuth, unpublished) covered the child's development and current behaviour and employed the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III-R) criteria for externalizing and internalizing disorders of childhood. The teacher interview (the Telephone Teacher Interview [TTI]; Schachar and Tannock, unpublished) followed the same basic format as the PICS but focused on 3 diagnostic areas in detail (ADHD, oppositional defiant disorder, and conduct disorder) and screened for internalizing disorders (for example, separation anxiety disorder, depression). The PICS and TTI were administered by trained clinicians who rated the behaviour on a 4-point scale of severity and frequency based on descriptions of behaviour elicited from the informant. These semistructured interviews have been demonstrated to be reliable measures in diagnosing child psychopathology (10). All 81 children met diagnostic criteria for "pervasive" ADHD. This was defined as reaching the DSM-III-R criteria on either the parent or teacher interview and having at least 5 ADHD symptoms endorsed in the other interview.

In addition to the diagnostic interviews, parents and teachers completed various rating scales and questionnaires to provide supporting information. The child assessment consisted of various measures of cognitive processing, academic achievement and psychosocial functioning. Among these measures were the short version of the Wechsler Intelligence Scale for Children – Revised (Vocabulary and Block Design subtests) (11) and the Wide Range Achievement Test – Revised (WRAT-3) (12). Less than 10% of the children were attending full-time special education classes in the regular school system. The children's performance on these measures can be found in Table 1.

### Treatments

**Medication.** After randomization, each child went through an initial 3- or 4-week blind titration phase. The dose of medication or placebo was started at 5 mg twice daily, once in the morning and once at lunch. The dose was increased weekly in 5 mg steps, to a target dose of 0.7 mg/kg body weight in a single oral dose administered twice daily. The dose of medication could be increased or decreased as deemed necessary by the study physician to minimize side effects while trying to reach the target dose. Parents were told it was appropriate for children to take the medication 7 days weekly, including

**Table 1. Characteristics of children (N = 81) with attention-deficit hyperactivity disorder (ADHD)**

Characteristics	Mean (SD)	Range
Age in years	8.37 (1.57)	5.3–12.3
Estimated IQ	109.90 (15.38)	80–144
Reading standard score	88.73 (19.95)	52–147
Spelling standard score	85.74 (16.43)	48–132
Math standard score	92.46 (17.62)	45–148
Mean number of ADHD symptoms reported by parent	10.38 (2.77)	5–14
Mean number of ADHD symptoms reported by teacher	10.53 (2.72)	5–14

school holidays, but were given discretion to omit weekend and holiday doses. If families asked to change to the alternate medication (MPH or placebo), a second blind titration was undertaken to achieve the target dose.

**Parent Programs.** Parents were assigned to a parent support group or a parent-training group. The parent support group was organized by parents and had a professional advisory committee. The conveners of the parent support group were aware that some families were participating in a research study but did not know which families. Individual meetings were attended by 35 to 250 participants, the majority of whom were not part of the treatment study. The 12 monthly meetings were conducted in the early evening and included opportunities for sharing information about community resources, examining resource materials (for example, books on ADHD), and hearing invited speakers on topics such as collaborating with school teachers and the role of medication. No specific teaching of child-management strategies was included, although tapes and books on the subject were available.

The parent-training group implemented the model by Cunningham and others (13), which has been demonstrated to be effective in reducing behaviour problems in young children with disruptive behaviour disorders. The program followed an approach of coping-modelling and problem-solving, in which participants formulated solutions to specific child-management problems after observing videotapes depicting these problems. These groups were facilitated by 2 of 3 experienced group leaders. Participants were parents of children in the treatment study and of other outpatients, and group leaders were unaware of which participants were enrolled in the treatment study. To ensure the program's integrity, leaders participated in formal training, conducted groups according to a detailed manual (13), and used a checklist to monitor program execution. All sessions were recorded and viewed by leaders on a regular basis. A fourth trained leader reviewed one-third of the videotapes and checked for the presence of key elements. Virtually 100% of the session elements were rated as present in these videotapes.

## Measures

The ADHD Knowledge and Opinion Scale (AKOS) (6) was the main experimental measure used in the present study but was slightly modified (5 items evaluating parent opinions of parent support groups were added to the original AKOS). The first section of the AKOS employs 15 true-false questions assessing parent knowledge of ADHD, including symptoms, characteristics, causes, diagnosis, and treatments of ADHD. For the second section, parents were asked to respond to a series of 24 statements regarding their opinion of various treatment options for ADHD. Specifically, 9 statements explored opinions regarding stimulant medication, 5 statements determined opinions about parent training or counselling, and 5 statements assessed opinions of parent support groups. The remaining 5 statements addressed parents' perceived levels of competence with respect to child management. The parent responded to these statements on a 4-point Likert scale, ranging from "strongly disagree" to "strongly agree" (Table 2).

## Procedure

Mothers completed the AKOS during the course of the diagnostic assessment. The children's diagnostic profile and the families' decision whether or not to participate in the extended treatment study were not discussed until after the entire assessment process was complete. This ensured that families were not aware of their randomized assignment (MPH versus placebo and parent training versus parent support) and, therefore, not influenced by these parameters when completing the AKOS. Families' adherence to the general protocol was monitored over 12 months with weekly contact for the first month, followed with telephone contact every 2 months and quarterly hospital appointments with a physician and study staff. Regular telephone contact with the child's teacher was part of the monitoring procedure. Additional consultations were provided when requested by parents or deemed necessary by study clinicians. Adherence to treatment components was assessed by pill counts (medication) and attendance records (parent groups). The AKOS was once again completed by 64 mothers at the end of the 12-month study period.

## Analysis

The Statistical Package for Social Sciences (SPSS) was used for all analyses. Study results are presented in 5 sections addressing 5 specific questions of interest. The first 4 sections use the AKOS data collected at baseline (that is, prior to diagnosis and random assignment of treatments) and include data from 81 parent-completed AKOS forms. The first section employs paired *t*-tests to determine parents' preferences between various treatments. The second section uses bivariate correlations to examine the relationship between knowledge of ADHD and opinions of various treatments. To determine whether knowledge and opinions predict enrolment and adherence to treatment, the third and fourth sections use logistic regressions, with enrolment and adherence as the predicted

**Table 2. Examples of questions from the ADHD Knowledge and Opinion scale (AKOS)**

Subscale	Example questions
Knowledge	Very few children with ADHD have any problems with attention or restlessness when they become teenagers. The medication used for ADHD has very different effects upon children with ADHD than those without the disorder.
Competence	In general I think I know how to handle my child pretty well. My child's behaviour is so difficult to control that sometimes I feel like a failure as a parent.
Medication	I believe that medication could help my child with ADHD I believe that medication for ADHD is basically safe and has only minor side-effects.
Parent training/counselling	I could use some professional counselling to help me and my family deal with my child in better ways. Our family could benefit from counselling sessions to learn how to cope better with our child with ADHD.
Parent support	I could learn from meeting with a group of parents who have similar problems as our family I feel that I would benefit from meeting other parents who also have children with ADHD.

**Table 3. Baseline scores on the ADHD Knowledge and Opinions Scale (AKOS) (N = 81)**

	Possible score	Mean (SD)	Range
Knowledge	0–15	7.99 (2.96)	0–14
Competence	5–20	13.25 (2.52)	7–20
Medication	9–36	24.23 (3.30)	15–30
Parent training	5–20	15.62 (2.04)	10–20
Parent support	5–20	15.81 (2.04)	9–20

variables and AKOS scores on the knowledge and opinion scales as predictors. The final section incorporates scores on the AKOS for 64 families at baseline and exit (that is, after 12 months' involvement in the treatment trial). Paired *t*-tests are used to compare parents' level of knowledge and opinions of treatment before treatment and after 12 months.

## Results

### 1) Preferred Treatment Modality

The mean scores on the knowledge and opinions scales of the AKOS can be found in Table 3. At baseline (N = 81), the 2 nonpharmacological interventions (parent support and parent training or counselling) were viewed more favourably than the pharmacological intervention (medication versus parent support,  $t[80] = -7.75, P < 0.01$ ; medication versus parent training,  $t[80] = -6.92, P < 0.01$ ). However, there were no significant differences between parents' opinions of the 2 parent groups (parent training versus parent support,  $t[80] = 1.11, P = 0.27$ ).

### 2) Knowledge of ADHD and Opinions of Various Treatments

Based on the entire sample of parents, a higher level of knowledge was significantly correlated with more positive opinions of parent groups (parent support:  $r = 0.29, P < 0.01$ ; parent training:  $r = 0.27, P < 0.01$ ). Parents who held high opinions of one type of parent group also held high opinions of the other type ( $r = 0.69, P < 0.01$ ). Knowledge of ADHD was not associated with parents' opinions of medication ( $r = -0.14, P = 0.22$ ).

### 3) Enrolment Into Treatments

Enrolment into treatments was considered positive if parents attended at least 1 parent group or had their child take at least 1 pill. Based on this definition, 68 families (84.0%) enrolled into the medication treatment, and 52 families (64.2%) enrolled into the parent-group treatment. There were no differences in enrolment for the 2 parent groups (parent training and parent support) or for the medication groups (MPH and placebo). Logistic regressions indicated that families were more likely to enrol in medication if they had higher knowledge of ADHD (Wald = 4.97,  $P < 0.05$ ) and a higher opinion of medication (Wald = 13.03,  $P < 0.01$ ). The same variables were found to predict enrolment into a parent group (knowledge: Wald = 4.97,  $P < 0.05$ ; medication opinion: Wald = 8.82,  $P < 0.01$ ).

### 4) Adherence Over 12 Months

Adherence to treatment was defined as greater than 50% of pills taken (based on pill count) or more than 50% of parent sessions attended (based on attendance records) and was assessed for only those families who had enrolled in the treatments. It was found that 36 of 68 (52.9%) families adhered to their assigned medication treatment, with a significant difference in adherence rates for the MPH versus placebo groups (MPH: 25 of 35 [73.5%]; placebo: 11 of 34 [32.4%];  $\chi^2 = 11.57, P < 0.01$ ). For parent groups, 30 of 52 (57.7%) families adhered over the 12 months. The adherence rates for the 2 parenting groups did not differ significantly (parent training: 18 of 26 [69.2%]; parent support: 12 of 26 [46.2%];  $\chi^2 = 2.84, P = 0.09$ ). The results of the logistic regressions indicated that adherence rates for the parenting groups and the medication groups were not significantly related to baseline parental knowledge of ADHD or opinions of treatment.

### 5) Change in Parents' Knowledge and Opinions

The mothers of 64 children completed the AKOS at the end of the 12-month treatment trial. Mean scores on the AKOS at baseline and at 12 months for these 64 families can be found in Table 4. Significant improvements were found on AKOS subscales measuring knowledge of ADHD ( $t[63] = 5.01, P < 0.01$ ) and parent-perceived competence levels ( $t[63] = 1.98, P < 0.05$ ). Parents' opinions of parent training/counselling decreased significantly over the 12 months ( $t[63] = 2.71, P < 0.01$ ). There were no significant changes in parents' opinions

**Table 4. Scores at baseline and 12 months on the ADHD knowledge and opinions scale (AKOS)**

Subscale	Baseline (N = 64)		12 Months (N = 64)	
	Mean (SD)	Range	Mean (SD)	Range
Knowledge	8.20 (2.86)	0–14	9.67 (2.53)	1–13
Competence	13.09 (2.40)	8–20	13.62 (2.30)	7–18
Medication	24.75 (2.59)	19–30	25.33 (3.35)	16–30
Parent training	15.59 (2.12)	10–20	14.75 (2.62)	8–20
Parent support	15.69 (2.05)	9–20	15.65 (2.46)	10–21

of medication or parent support groups (medication:  $t[63] = 1.35$ ,  $P = 0.18$ ; parent support:  $t[63] = 0.13$ ,  $P = 0.90$ ).

## Discussion

The main findings of the study are 1) parents of ADHD children provided more favourable ratings for nonpharmacological interventions compared with pharmacological interventions; 2) higher knowledge of ADHD was associated with more favourable opinions of nonpharmacological interventions but not pharmacological interventions; 3) enrolment in pharmacological and nonpharmacological interventions was related to higher knowledge of ADHD and more favourable opinions of medication; 4) adherence to pharmacological and nonpharmacological treatments was not related to initial knowledge of ADHD or opinions of treatments; and 5) over the course of participating in a 12-month treatment trial, parents had a higher level of knowledge of ADHD and competence and a decreased opinion of parent training/counseling.

Finding higher acceptability ratings of nonpharmacological interventions compared with pharmacological interventions is consistent with previous research employing both analogue and naturalistic methodologies (for example, 14–16). It is particularly interesting here because nonpharmacological interventions are rated as the most acceptable yet have lower enrolment and adherence rates than does pharmacological intervention.

Findings regarding the relationship between knowledge of ADHD and acceptability ratings of various treatments are inconsistent. We did not find a relationship between knowledge of ADHD and opinions of medication, although previous research has shown both positive (7,8) and negative (6) relationships. In contrast to previous studies that have not found a significant relationship between knowledge and acceptability of nonpharmacological interventions (6–8), we did find a small but significant correlation. The differences in findings may be related to the time at which the acceptability of treatments was assessed (prior to diagnosis or after diagnosis), different methods of assessing acceptability (different measures and methodology), type of informant (in naturalistic studies, the child's mother or father; in analogue studies, university

students or parents of nonidentified children), or differences in samples selection (general assessment clinic, randomized trial, analogue methodologies).

This is the first study to explore the role of parental knowledge of ADHD and opinions of treatments in the enrolment and adherence in a long-term treatment trial. The importance of this is underscored by the long-term nature of many of the treatments used for ADHD (7). It was found that parental knowledge and opinions play a significant role in the family's decision to enrol in treatment but not in its decision to adhere to the treatment over the long term. No other study has differentiated between enrolment and adherence; however, several studies have found that knowledge and acceptability ratings are not related to adherence over shorter durations (for example, 7). The current findings suggest that improvements in knowledge and opinions of treatments may result in more families enrolling in treatment, which is the first step to improving adherence to treatment. A preliminary study indicated that having parents watch videos on ADHD at the time of diagnosis could improve knowledge and enrolment in various treatments (17).

Previous research has indicated that parental knowledge of ADHD and acceptability ratings may change after exposure to the treatment. The reasons for these changes have been attributed to several factors, including effectiveness of treatment and treatment integrity (14,18,19). We found positive changes in parents' knowledge of ADHD and perceived competence levels after 12 months' participation in the clinical trial. However, acceptability ratings remained unchanged for medication and parent support groups and were less favourable for parent-training groups. Unfortunately, the large number of families who did not enrol in the parent groups (36%) and the high number of families who did not adhere to these groups (40%) make it difficult to assess the reasons for the lack of or negative change in acceptability. This problem is not unique to the current study, as compliance rates for nonpharmacological interventions have been found to be similar across several studies (for example, 7,5,20).

There are several limitations to the current study. First, enrolment and adherence were defined according to minimal criteria (that is, enrolment was defined as taking 1 pill or attending 1 parent group, and adherence was defined as taking at least 50% of the pills and attending at least 50% of the parent groups), and therefore may not generalize to more stringent definitions of these constructs. Second, although the analyses resulted in statistically significant results, typically these reflected small effect sizes; the clinical significance of these findings needs to be interpreted with caution. Third, logistical information (for example, distance to travel to parent groups, child care arrangements) that may have impacted on enrolment and adherence was not available in the current study.

To extrapolate from the findings of the current study, clinicians may want to focus on providing information to parents prior to offering treatment choices as well as exploring barriers to enrolment and adherence (for example, financial or

### Clinical Implications

- Clinicians need to be aware of the potential impact of mothers' knowledge of attention-deficit hyperactivity disorder (ADHD) and opinions of treatments on treatment enrolment.
- To increase enrolment, clinicians may want to focus on providing information regarding ADHD and treatment options prior to offering treatment choices.
- Given that treatment adherence did not appear to be related to mothers' knowledge and opinions of ADHD and treatments, clinicians should explore possible barriers to treatment adherence with families (for example, child care arrangements, costs).

### Limitations

- Enrolment and adherence were defined by minimal criteria and therefore may not generalize to more stringent definitions of these constructs.
- Given the small effect sizes found for significant results, the clinical significance of these findings needs to be interpreted with caution.
- The study did not include all potential variables which may contribute to families' decisions to enrol in and adhere to treatments.

logistic). Perhaps, with an increased knowledge of ADHD, parents may formulate more positive opinions of these treatments. This could result in greater enrolment and therefore adherence to the treatments, which has been shown to be related to more positive long-term outcomes for children with ADHD.

Future research should focus on determining the barriers to enrolment and adherence, as these may be the most urgent research targets—many treatments known to be effective are severely limited by low enrolment and adherence. Also, experimental studies of interventions that increase knowledge of ADHD and opinions of various treatments may help in engaging more families in treatment for their children with ADHD.

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### Résumé

**Objectif :** Cette étude observe la relation entre la connaissance qu'ont les parents du trouble d'hyperactivité avec déficit de l'attention (THADA) et les opinions sur le traitement, ainsi que les répercussions sur l'adoption et l'observance d'interventions pharmacologiques et non pharmacologiques sur les enfants souffrant du THADA.

**Méthode :** Les participants à l'étude étaient les parents de 81 enfants qui satisfaisaient aux critères du THADA et qui avaient été dirigés vers une étude de traitement du THADA faisant appel à des stimulants et à des groupes de parents. Les mères ont répondu à une version modifiée de l'échelle de connaissance et d'opinion sur le THADA (AKOS) avant de recevoir une rétroaction sur le diagnostic et avant que les familles ne décident de participer à un essai randomisé de 12 mois [médication (méthylphénidate ou placebo) et groupes de parents (formation ou soutien)]. L'adoption et l'observance du traitement ont été surveillées au cours des 12 mois de l'essai, et les familles qui participaient encore à l'étude après 12 mois ont répondu à une autre AKOS modifiée.

**Résultats :** Un niveau supérieur de connaissance du THADA semble être lié à des opinions plus favorables sur les groupes de parents mais pas sur la médication. En outre, les parents qui ne connaissaient pas le THADA étaient plus susceptibles d'adopter les deux traitements, pharmacologique et non pharmacologique. L'observance des traitements tant pharmacologique que non pharmacologique n'était pas prédite par la connaissance des parents du THADA ou par les opinions sur le traitement.

**Conclusion :** La connaissance qu'ont les parents du THADA et les opinions sur les traitements jouent un rôle important dans l'adoption de traitements pour les enfants souffrant du THADA. Donner de l'information aux parents sur le THADA avant de présenter les modes de traitement pourrait avoir un effet favorable sur l'adoption d'un traitement et par conséquent, sur l'observance de celui-ci.