Published in final edited form as:

Acad Pediatr. 2012 September ; 12(5): 445–455. doi:10.1016/j.acap.2012.04.009.

Development of an Instrument to Measure Parents' Preferences and Goals for the Treatment of Attention Deficit-Hyperactivity Disorder

Alexander G. Fiks, MD, MSCE^{*,†,§,+}, Stephanie Mayne, MHS^{*,§}, Cayce C. Hughes, MPH^{*,§}, Elena DeBartolo^{*,§}, Carina Behrens, MD^{*,§}, James P. Guevara, MD, MPH^{*,§,+}, and Thomas Power, PhD^{+,€}

^{*}The Pediatric Research Consortium (PeRC), The Children's Hospital of Philadelphia

[§]Center for Biomedical Informatics (CBMI), The Children's Hospital of Philadelphia

[†]Center for Pediatric Clinical Effectiveness, The Children's Hospital of Philadelphia

[§]PolicyLab, The Children's Hospital of Philadelphia

⁺Department of Pediatrics, Perelman School of Medicine at the University of Pennsylvania

[€]Psychiatry, Perelman School of Medicine at the University of Pennsylvania

Abstract

Objectives—To describe the development and validation of an instrument to measure parents' attention deficit-hyperactivity disorder (ADHD) treatment preferences and goals.

Methods—Parents of children 6–12 years diagnosed with ADHD in the past 18 months were recruited from 8 primary care sites and an ADHD treatment center (autism excluded). A 16-item medication and 15-item behavior therapy preference scale and a 23-item goal scale, developed following literature review, 90 parent and clinician semi-structured interviews, and input from parent advocates and professional experts, were administered to parents. Parent cognitive interviews confirmed item readability, clarity, content, and response range. We conducted an exploratory factor analysis, assessed internal consistency and test-retest reliability, and construct and concurrent validity.

Results—We recruited 237 parents (mean child age 8.1 years, 51% Black, 59% from primary care, 61% of children medication naive). Factor analyses identified 4 medication preference subscales (treatment acceptability, feasibility, stigma, and adverse effects, Cronbach's α 0.74 to 0.87); three behavior therapy subscales (treatment acceptability, feasibility, and adverse effects, α 0.76 to 0.83); and three goal subscales (academic achievement, behavioral compliance, and interpersonal relationships, α 0.83 to 0.86). The most strongly endorsed goal was academic achievement. The scales demonstrated construct validity, concurrent validity ($r = 0.3$ – 0.6) compared to the Treatment Acceptability Questionnaire and Impairment Rating Scale and moderate to excellent test-retest reliability (ICC = 0.7–0.9).

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Corresponding Author: Alexander G. Fiks, MD, The Pediatric Generalist Research Group, The Children's Hospital of Philadelphia, 3535 Market Suite, Room 1546, Philadelphia, PA 19104, Phone: 267-426-2304, Fax: 267-426-0380, fiks@email.chop.edu.

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Financial Disclosure and Conflicts of Interest: None.

Conclusions—We developed a valid and reliable instrument for measuring preferences and goals for ADHD treatment, which may help clinicians more easily adhere to new national treatment guidelines for ADHD that emphasize shared decision making.

Keywords

ADHD; Shared Decision Making; Patient Preference; Practice-Based Research

Introduction

Shared decision making (SDM) involves the active participation of both clinicians and families in treatment decisions, the exchange of information, discussion of preferences, and a joint determination of the treatment plan.¹ This process helps families and clinicians balance the risks and benefits of different options in the context of personal values. Clinical trials have shown that families participating in SDM using standardized decision aids had increased knowledge, less uncertainty, greater participation in decision making, and were less likely to remain undecided about treatment.² Based on these findings, the Institute of Medicine (IOM) has prioritized research on SDM in the setting of chronic illness³ and the 2010 Patient Protection and Affordable Care Act supports the implementation of SDM in clinical settings.⁴ The assessment of treatment preferences⁵ and goals from families provides a foundation for SDM.

ADHD is an ideal prototype for SDM in pediatrics because it results in impaired academic achievement, self-esteem, and interpersonal relationships for over 4 million children,^{5, 6} there are multiple evidence-based treatment options,^{7, 8} and personal and cultural values influence their selection.^{9–12} Even though ADHD has many adverse consequences, families, especially those in minority groups, are often reluctant to accept effective treatments for ADHD which include both stimulant medication and behavior therapy, alone or in combination.^{13, 14} In response, new national guidelines and a revised toolkit for ADHD treatment from the American Academy of Pediatrics (AAP) recognize this problem, stress that “family preference is essential in determining the treatment plan,” and provide forms to list treatment goals.^{8, 15} Despite this prioritization, clinicians continue to lack validated tools to elicit from families their preferences and goals for ADHD treatment. In fact, no measures have been developed to formally determine the goals and multiple domains of preference of parents of children with ADHD. To address these knowledge gaps in a clinical context ideal for SDM, this study was designed to develop and validate an instrument to assess parents’ ADHD treatment preferences and goals.

Methods

Patient population

Subjects were recruited from 4 urban and 4 suburban primary care practices within The Children’s Hospital of Philadelphia (CHOP) Pediatric Research Consortium (PeRC), a primary care practice-based research network, and the CHOP Center for Management of ADHD, a specialty clinic staffed by an interdisciplinary team. These settings were chosen in order to develop an instrument that was useful in distinct practices settings and with a diverse population of families. Eligible parents had children between 6 and 12 years who were enrolled in grades kindergarten or higher, had been diagnosed with ADHD within the last 18 months, and were English speaking. Children with autism spectrum disorders and intellectual disability were excluded. In the primary care practices, children were diagnosed by a pediatrician using the Vanderbilt Rating Scale.^{16, 17} For children diagnosed at the ADHD Center, a combination of the following were used: structured diagnostic interview

(K-SADS-PL)¹⁸, the ADHD Rating Scale-IV,¹⁹ Behavior Assessment System for Children (BASC)²⁰, and an interview with parents to evaluate impairments.

A member of the research team approached eligible families, identified by clinic staff or using rosters generated from the electronic medical record, introduced the study and obtained consent. The final survey was completed within 20 minutes. Participants received \$10 as an incentive. Chart review was then used to confirm the date of ADHD diagnosis, ADHD subtype, and comorbidities. Subjects were excluded if chart review demonstrated that they were not eligible.

Instrument Development

The preference and goal items were developed after the completion of 60 semi-structured interviews with parents and 30 with clinicians addressing shared decision making in ADHD.²¹ In addition, we consulted an advisory panel with expertise in ADHD comprised of 2 practicing general and 2 developmental pediatricians, a school psychologist, a medical anthropologist, and a leader of a national ADHD advocacy group. Based on a review of existing measures assessing treatment acceptability, we used the Treatment Evaluation Inventory²² and the ADHD Knowledge and Opinion Rating Scale (AKOS) to inform our preference measure.²³ We included medication and behavior therapy as the 2 treatment options in the preference scales because they were endorsed by practice guidelines from the American Academy of Pediatrics (AAP) and by results of the Multimodal Treatment of ADHD (MTA) Study.^{7,15} Although we found no instrument that directly captured ADHD treatment goals, we considered items from the Life Participation Scale for ADHD, an instrument that assesses treatment-related improvements in adaptive functioning, including quality of life, social development, and emotional regulation.^{24–26} Ultimately, we developed a draft instrument with three separate sections: (1) medication treatment preferences, (2) behavior therapy treatment preferences, and (3) treatment goals. Iterative rounds of review lead to revisions in the scales' content as well as technical elements including response categories and word choice. To incorporate the perspectives of children, we reviewed the instrument with 3 children (10 years of age) who had been diagnosed with ADHD. These children responded favorably to the instrument and did not suggest changes.

Survey Pilot Phase

We then pilot-tested the instrument with 6 parents of children recently diagnosed with ADHD and conducted cognitive interviews. These 30–45 minute interviews assessed readability, clarity, response range, and content and lead to the revision of multiple items and the rewriting of the survey instructions. The finalized measure included 3 sections, 15 items addressing preferences for behavior therapy, 16 items for medication treatment, and 23 goal items with responses Likert-scaled from 0 to 4. An example of the introduction, format, and response options for these scales are shown in Figure 1. Each goal scale item included two parts, the first indicating if each item was a concern for the parent now and the second indicating if the parent wanted to work on this concern with the child's doctor or psychologist. Because the responses for these items were highly correlated ($r=0.83–0.94$), all subsequent analyses are presented based exclusively on parent responses to the statement "This is a concern for me now."

Missing Data

The percentage of missing data was determined for each item. Missing data was rare. There were no more than 5% of subjects missing data for any of the preference and goal items; also, only 3, 4 and 4 out of 237 parents had more than 2 missing values for the medication preference scale, behavior therapy preference scale, and goals scale, respectively. We used multiple imputation methods and imputed 10 data sets to complete missing data on the

preference and goal scale items (5% missing for each item) and for baseline behavior therapy receipt (14% missing) in a manner designed to avoid bias in our results and produce correct confidence intervals.²⁷ All statistical analyses included the imputed data.

Factor Analysis

To identify the latent structure of the preference and goal scales, we conducted exploratory common factor analysis.^{28–30} The number of factors retained for rotation was determined using minimum average partials,³¹ parallel analysis,³² and Bartlett's Test³³ supplemented by a visual scree test.³⁴ Factor solutions were rotated orthogonally (Varimax) and obliquely (Promax) to determine the most parsimonious factor structure. Factor analysis yields patterns of coefficients, known as factor loadings, that indicate the strength of the association between individual items and proposed factors. Pattern coefficients 0.40 were predetermined to indicate a salient association between an item and factor. Non-salient items and those that loaded on multiple factors were dropped from the scale to obtain a simple structure. Factor structures were evaluated according to the following criteria: (1) three or more unique and salient loadings on each factor; (2) internal consistency reliability (Cronbach's alpha 0.70 for the overall scale and for each factor³⁵); and (3) theoretical and clinical meaningfulness of the proposed factors.

Statistical Analyses

We described the study population using descriptive statistics. Content validity of the scales was established through the previously described process of instrument development. Once the factor structures of the preference and goal scales were identified, we computed the mean ratings of the items of each scale and of each factor (range: 0–4). Accounting for the 10 imputed datasets, subscale means were then compared. The mean item ratings were then used to assess construct validity, a measure of whether a scale performs as hypothesized.³⁶

To establish construct validity, we used a series of linear regression models to test pre-specified hypotheses. We hypothesized that, in the subset of children who were diagnosed at least 3 months prior to enrollment, preference ratings would indicate a greater acceptance of medication among parents of children currently receiving medication for ADHD treatment, and a greater acceptance of behavior therapy among parents of children currently receiving that treatment. We also hypothesized that parents who were at an earlier stage of decision making according to an item from the Ottawa Health Decision Centre toolkit would have lower mean item ratings for both medication and behavior therapy preferences.³⁷ In addition, we hypothesized that parents of children with combined-type versus inattentive ADHD would have higher goal item ratings for the domain of behavioral compliance, that parents of children with problematic performance in academic areas (assessed by the Vanderbilt Performance Scale^{16, 17}) would have higher goal item ratings for the domain of academic achievement, and that parents of children with Oppositional Defiant Disorder (ODD) would have higher goal item ratings for the domain of interpersonal relationships. P values <0.05 were considered significant.

In order to test the concurrent validity of the preference scale, we simultaneously administered the Treatment Acceptability Questionnaire, Parent version (TAQ-P),³⁸ a validated measure of the acceptability of medication and behavior therapy. To test the concurrent validity of the goal scale, we administered the Impairment Rating Scale, Parent version,³⁹ a reliable and valid instrument that assesses the impact of ADHD in distinct contexts. Using Pearson correlation coefficients and adjusting for multiple comparisons using Sidak's correction,^{40, 41} we correlated the mean overall and subscale scores for the preference scales with those of the TAQ-P and the mean overall and subscale goal scores

with those of the Impairment Rating Scale. Correlations were designated as small ($r=0.10-0.29$), medium ($r=0.30-0.49$), and large ($r=0.50$).⁴²

Test-Retest Reliability

Twenty-one families were re-administered the survey by phone 7–14 days following the completion of initial measures. Test-retest reliability for the overall scales and for individual factors was determined using an interclass correlation coefficient (ICC) with a value of 0.80 indicating excellent agreement, between 0.61 and 0.79 indicating moderate agreement, and between 0.41 and 0.60 indicating fair agreement.

Factor analysis was performed using SAS version 9.1 (SAS Institute, Cary, NC), and remaining statistical analyses were performed using Stata versions 10.0 and 11.0 (StataCorp, College Station, TX). The study was approved by the CHOP Institutional Review Board.

Results

Study Population

Characteristics of participants are described in Tables 1 and 2. We approached a total of 205 potential subjects at CHOP primary care centers and recruited 141 eligible subjects from this population, with 21 (10%) refusing. The remaining 43 were found to be ineligible. Those who refused were significantly more likely to identify their race as white or other ($p=0.05$), and have an older child ($p=0.04$). We recruited an additional 96 subjects from the CHOP ADHD Center, with only 2 (2%) refusing. These subjects did not differ significantly by race or gender from the overall population receiving care at the ADHD Center. Our total enrollment included 237 eligible participants.

Factor Analysis of the Medication Preference Scale

A 4-factor oblique solution best met the criteria for factor retention for the medication preference scale. The 4 domains were treatment acceptability, feasibility, stigma, and adverse effects, each with Cronbach's α coefficient 0.7 (Table 3A). All of the items loaded significantly on one factor, and were retained in the final model. This factor solution accounted for 59% of the total variance. The "acceptability" subscale addressed overall comfort with and belief in the effectiveness of medication, "feasibility" included items related to practical barriers to medication treatment, "stigma" items measured negative perceptions of the child or family by others due to medication treatment, and "adverse effects" addressed issues regarding side effects of medication.

Factor Analysis of the Behavior Therapy Preference Scale

A 3-factor oblique solution best met the criteria for factor retention for the behavior therapy scale. The 3 domains were treatment acceptability, feasibility, and adverse effects, each with Cronbach's α coefficient 0.7 (Table 3B). Fourteen of fifteen items loaded on any one of the factors, and were retained. This factor solution accounted for 49% of the total variance. The "acceptability" subscale addressed overall comfort with and belief in the effectiveness of behavior therapy, "feasibility" included items related to practical barriers to behavior therapy, and "adverse effects" perceived negative consequences of receiving behavior therapy for the child.

Factor Analysis of the Goals Scale

A 3-factor oblique solution best met the criteria for factor retention for the goals scale. The three domains were academic achievement, behavioral compliance, and interpersonal relationships each with Cronbach's α coefficient 0.8 (Table 3C). Sixteen items were

retained in the final instrument. We dropped six items that did not load or loaded on multiple factors. This factor solution accounted for 50% of the total variance. The “academic achievement” subscale addressed learning, “behavioral compliance” included items related to following rules at school and home, and “interpersonal relationships” included items addressing getting along with peers and family members (see the online appendix for the final preference and goal scales).

Mean Item Ratings for Each Factor

Table 4 presents the mean rating for each factor and each item on the preference and goal scales. The mean item rating for the overall behavior therapy preference scale was significantly higher than the mean item rating for the medication preference scale ($p < 0.001$), suggesting that subjects overall had a greater preference for behavior therapy than for medication. Of medication rating subscales, scores were the lowest for acceptability and adverse effects ($p < 0.0001$), indicating that these were the most common barriers to medication treatment. For behavior therapy, feasibility scores were lowest ($p < 0.001$) suggesting that practical concerns were the primary barrier to parents preferring behavior therapy. On the goals scale, improved academic achievement was the most strongly endorsed goal (52% of the study population) followed by behavioral compliance (46%) and interpersonal relations (7%) (Table 4). 8% of the sample endorsed more than one goal most strongly.

Test-Retest Reliability

Twenty one of the first subjects recruited, who had similar characteristics to the overall sample ($p > 0.05$ for all comparisons), completed the instrument again 2 weeks after their initial enrollment. The preference and goal scale demonstrated excellent test-retest reliability for the overall scales, with an ICC of 0.9 for each overall scale. ICCs for the overall scales and subscales are shown in Table 5.

Construct Validity of the Preference and Goal Scales

The preference and goal scales performed as hypothesized (Tables 6 and 7). Subjects whose children were on ADHD medication at the study start had higher medication preference mean item ratings than those who were not ($p < 0.0001$). Although not statistically significant, patterns were similar for behavior therapy. Additionally, subjects who reported being at a later stage of decision making had higher medication preference means ($p < 0.0001$) and non-significantly higher behavior therapy scores ($p = 0.1$). Subjects who rated their children’s school performance as somewhat problematic or problematic had higher mean item ratings for the academic achievement goal domain than others ($p < 0.001$). Parents whose children were diagnosed with combined-type ADHD more strongly endorsed the goal of behavioral compliance than those whose children had inattentive type ($p < 0.001$). Finally, subjects whose children had a comorbid diagnosis of ODD had a significantly higher mean item rating for the interpersonal relationships goal domain than subjects whose children did not have ODD ($p < 0.001$).

Concurrent validity

The scales demonstrated concurrent validity. The medication preference scale was highly correlated with the Medication TAQ-P scores ($r = 0.60$), and the behavior therapy preference scale was moderately correlated with the Behavior Therapy TAQ-P scores ($r = 0.44$). Additionally, higher scores on the interpersonal relationships treatment goal domain were highly correlated with Impairment Rating Scale items addressing relationships with playmates and siblings ($r = 0.62$ and 0.61 , respectively), and moderately correlated with the items addressing relationships with parents and the overall family ($r = 0.31$ and 0.41 ,

respectively). The academic achievement goal domain was highly correlated with the Impairment Rating Scale item relating to school performance ($r=0.62$).

Discussion

Clinicians currently lack tools for measuring families' preferences and goals for ADHD treatment, a foundation for SDM and a priority in new guidelines from the American Academy of Pediatrics.⁴³ Through an iterative process that included literature review and engaged a diverse group of families, clinicians and content experts, we developed a reliable and valid instrument to assess parents' preferences and goals for ADHD treatment. Each scale and subscale demonstrated internal consistency reliability with $\alpha = 0.74$, above the standard threshold of 0.7. Scales performed as hypothesized in the analysis of construct validity, demonstrated moderate to high concurrent validity, and had excellent test-retest reliability.

Our results extend prior research findings by using exploratory factor analysis to identify domains that shape parents' preferences for medication and behavior therapy. While previous scales including the TAQ-P measured only the acceptability of ADHD treatment,^{22, 23, 38} we included items addressing multiple dimensions of preference, including those that might be especially salient for minority groups.^{10, 13, 14, 43–45} Through this process, we identified four factors that influence medication preference: treatment acceptability, feasibility, stigma and adverse effects. Among these factors, scores for acceptability and adverse effects were lowest suggesting that these were the most important barriers for parents to medication treatment. In contrast to medication, we found three factors that shaped behavior therapy preference: acceptability, adverse effects and feasibility. Consistent with prior studies that have highlighted practical barriers to behavior therapy receipt,^{21, 46} we found that feasibility scored lowest among behavior therapy preference factors, which suggests that families identify practical barriers as most important in limiting participation in behavior therapy.

While prior instruments including the Impairment Rating Scale have assessed the impact of ADHD on different aspects of a child's life,³⁹ no prior instrument has been developed to assess families' goals for ADHD treatment. Our results indicate that families consider goals in 3 broad domains: academic achievement, behavior compliance, and interpersonal relationships. Highlighting the need to coordinate ADHD care, each domain spans more than one setting; academic achievement depends upon success in the classroom and homework completion, behavior compliance necessitates children following both family and school rules, and improving interpersonal relationships requires addressing interactions with teachers, peers, and family. Among the goal domains and consistent with existing literature on ADHD,⁴⁷ academic achievement was the most commonly endorsed goal, rated highest by 52% of the study population. However, 46% of parents most wanted to address behavior problems, and 7% interpersonal relationships. Reflecting that problems in ADHD span multiple domains for individual children, families sometimes endorsed multiple goals.⁷

The variation in goals between families underscores the importance of measuring goals in order to match families with evidence-based treatments most likely to achieve the outcomes they prioritize. For example, although medication for symptom control may be beneficial to help families reach any of these goals,⁷ children with academic problems may especially benefit from educational consultation with reading or math specialists, organizational skills training, or behavior therapy focused specifically on homework strategies.⁴⁷ In contrast, those prioritizing improved behavior may benefit from behavior therapy focused on parent training and consultation with the teacher in order to foster family-school collaboration.^{47, 48} To improve interpersonal relationships, social skills training accompanied by behavior

therapy focused on promoting effective peer relationships, such as through supervised play, may be most beneficial.^{47, 48} As these examples illustrate, by tailoring evidence-based treatment to match priorities for families, goal-directed care has the potential to improve outcomes. Prospective study is warranted.

Targeting treatment toward families' goals with evidence-based treatments they prefer may also contribute to improved treatment adherence in ADHD. Although systematic reviews have found that adherence strongly predicts improvement for children on all ADHD treatments,⁴⁹ multiple studies have documented limited adherence to treatment even in tightly controlled research settings.^{13, 14, 50–52} Reflecting challenges in promoting adherence, research has shown that treatment acceptability alone is not associated with improved adherence in ADHD.²³ Despite these barriers, the approach of measuring and targeting treatment toward families' goals may directly promote adherence since adherence depends upon families recognizing that their regimen is beneficial.⁵³ In addition, by measuring multiple dimensions of preference as opposed to only acceptability, clinicians may be able to more effectively elicit and address obstacles to treatment that could compromise adherence. Additional research will be needed to assess the benefits of this approach in clinical practice.

This study had several limitations. While the study sample included an even balance of white and black parents from diverse practice settings, only 4% of the sample was Hispanic and all study practices were from one health system in a single region of the United States, potentially limiting generalizability. Additionally, all study subjects were receiving care for ADHD. Findings may not reflect the perspectives of families who have not pursued treatment. Although subjects were diagnosed using valid instruments, the study team did not independently perform a standardized diagnostic evaluation. Our sample was too small to complete a confirmatory factor analysis or to conduct exploratory factor analyses for subpopulations. Although prior work has demonstrated the unique perspectives of children on ADHD treatment,^{54, 55} the measurement of children's preferences and goals was beyond the scope of this study.

We expect that this instrument will ultimately be helpful in both clinical practice and research. In order to facilitate clinical use, work will be needed to develop a manual and scoring system and pilot test optimal workflows for using the ADHD preference and goal instrument with families. A better understanding of the responsiveness of the instrument to changes in preferences and goals over time, the impact of prior treatment receipt on preferences and goals, as well as the association of measured preferences and goals with subsequent treatment choices and clinical outcomes will provide a foundation for use of the tool in research. With this tool, scholars should be able to better determine whether prescribed treatments are consistent with families' preferences and whether outcomes achieved match the families' priorities.

Conclusions

We developed a reliable and valid instrument to assess parents' preferences and goals for ADHD treatment. Although additional research is needed to confirm the factor structure of these scales, they may help pediatric clinicians meet new treatment guidelines from the AAP that prioritize SDM. Our analyses demonstrate that preferences for both medication and behavior therapy are multidimensional constructs. Salient barriers to treatment for individual families' may be better recognized using the preference measures. By measuring goals and tracking progress toward them, researchers and clinicians may also be better able to assess if current treatments are helping families achieve outcomes that they most value. Such an

approach may help both families and clinicians promptly identify and troubleshoot barriers to treatment success and keep families engaged in the treatment process.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

We thank Fran Barg, James Massey, the clinicians at CHOP's ADHD Center, Mark Ramos, and Russell Localio for their help with the conduct and analysis of this research. Marie Paxson of Children and Adults with Attention Deficit/Hyperactivity Disorder provided advice to the research team and reviewed the scales. We also thank the network of primary care physicians, the patients, and the families for their contributions to clinical research through the Pediatric Research Consortium at The Children's Hospital of Philadelphia.

Research Support: This research was supported by Award Number K23HD059919 from the Eunice Kennedy Shriver National Institute of Child Health & Human Development. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Eunice Kennedy Shriver National Institute of Child Health & Human Development or the National Institutes of Health.

Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
SDM	Shared Decision Making
IOM	Institute of Medicine
AAP	American Academy of Pediatrics
CHOP	Children's Hospital of Philadelphia
PeRC	Pediatric Research Consortium
BASC	Behavioral Assessment System for Children
AKOS	ADHD Knowledge and Opinion Rating Scale
MTA	Multimodal Treatment of ADHD Study
ODD	Oppositional Defiant Disorder
TAQ	P-Treatment Acceptability Questionnaire-Parent Version
ICC	Intraclass Correlation Coefficient

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What's New

The Institute of Medicine prioritized research to foster shared decision making (SDM) in chronic illness and guidelines for ADHD prioritize this process. We developed a novel instrument to assess parents' preferences and goals for ADHD treatment, a foundation for SDM.

A. Medication Preferences

Medication Treatment

Your doctor may offer your child a medicine for ADHD. Studies show that medication often helps children. The medicine can help your child focus. Medicine can also help control problem behaviors. Your child would take the medicine daily. It is usually very safe. Medicine can cause side effects. Common side effects include less appetite or sleep problems. Some children with heart problems may not be able to safely take medication. If needed, your doctor may order tests to check safety. Your doctor may then change the medicine or dose to best help your child. Medication for ADHD is not addictive.

Based on what you already know, please tell us how much you **agree** with the following statements about medication treatment for ADHD.

	I agree	Not at all	A Little	Somewhat	Very Much	Completely
1. Medication is a reasonable way to help my child.	0	1	2	3	4	
2. I feel comfortable working with my doctor to find the right medicine for my child.	0	1	2	3	4	
3. I would have trust in my doctor to treat my child's ADHD with medicine.	0	1	2	3	4	

B. Behavior Therapy Preferences

Child and Family Behavior Therapy

Behavior therapy involves helping you learn how to manage your child's behavior. Studies show that many children with ADHD are helped by behavior therapy. You may meet regularly with a counselor, psychologist, or therapist. You and your child will learn how to build a system that rewards good behavior at home and school. You may use rewards. These may include praise, attention from you, and privileges. Children may get rewards for finishing homework or following directions. You may also learn how to manage problem behaviors. For example, you may take away privileges. If your child loses control, you may send him or her to a quiet room. You will learn how to do this so that it is likely that your child's behavior will improve.

Based on what you already know, please tell us how much you **agree** with the following statements about child and family behavior therapy.

	I agree	Not at all	A Little	Somewhat	Very Much	Completely
1. Behavior therapy is a reasonable way to help my child.	0	1	2	3	4	
2. I feel comfortable working with a counselor/psychologist to help my child.	0	1	2	3	4	
3. I would trust in a counselor/psychologist to help my child.	0	1	2	3	4	

C. Goals

Reaching Your Goals

The doctor, nurse practitioner, or psychologist you work with will want to help you reach your goals for your child. To help you, they will want to know what type of changes you want to see from treatment.

Think about the concerns and goals that you have had for your child in the past month.

The following is a list of concerns that you may or may not have for your child. Some concerns are likely to be more important to you than others. Some concerns may be more important than others for you to address now.

First, indicate how important the concern is for your child. Then, indicate how important it is for you to address this concern now with your doctor or psychologist.

	Not at all	Slightly	Moderately	Very Much	Definitely
1. My child needs to be better at staying out of trouble at school.					
A. This is a concern for me now.	0	1	2	3	4
B. I want to work on this now with my doctor or psychologist	0	1	2	3	4
2. My child needs to be more caring toward adults in our family.					
A. This is a concern for me now.	0	1	2	3	4
B. I want to work on this now with my doctor or psychologist	0	1	2	3	4

Figure 1.

Instructions and Format for the ADHD Preference and Goal Instrument.

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Table 1

Demographic Characteristics of Parent Study Participants

	N (%)
Total Study Population	237
Parent Demographics:	
Race:	
White	110 (46%)
Black	120 (51%)
Other	7 (3%)
Hispanic	9 (4%)
Gender:	
Male	24 (10%)
Female	213 (90%)
Residence:	
Urban	131 (55%)
Suburban	106 (45%)
Education level:	
<High school	14 (6%)
High School graduate	63 (27%)
Some college or Associates degree	70 (29%)
Bachelors degree or higher	90 (38%)
Income:	
Low (\$0–\$32,999)	86 (36%)
Middle (\$33,000–\$54,999)	40 (17%)
High (\$55,000+)	104 (44%)
Not reported	7 (3%)
Employment:	
Working for wages	176 (74%)
Working without pay	23 (10%)
Unemployed	38 (16%)
Site of Care:	
Primary Care	141 (59%)
ADHD Center	96 (41%)
Stage of Decision Making ¹	
Have made a decision or are close to making one (later stage, 3–5)	122 (51%)
Have not made a decision (earlier stage, 0–2)	111 (47%)
Not reported	4 (2%)

¹ Stage of decision making determined using the Ottawa Decision Toolkit item that reads: “In thinking about treating your child who has or may be diagnosed with ADHD, would you say you: 0-haven’t begun to think about choices; 1-haven’t begun to think about the choices, but are interested in doing so; 2-are considering options now; 3-are close to selecting an option; 4-have already made a decision, but are still willing to reconsider; 5-have already made a decision and are unlikely to change your mind.”

Table 2

Demographics and Clinical Characteristics of Children with ADHD in the Study Population

	N (%)
Age, in years (Mean (SD)):	8.1 (1.6)
Gender:	
Male	171 (72%)
Female	66 (28%)
Baseline ADHD Treatment:	
On Medication	93 (39%)
Length of Time on Medication:	
6 months or less	36 (15%)
7–12 months	23 (10%)
>1 year	33 (14%)
Receiving Behavior Therapy	73 (31%)
Length of Time Receiving Behavior Therapy:	
6 months or less	21 (9%)
7–12 months	8 (3%)
>1 year	27 (12%)
Not reported	17 (7%)
ADHD Diagnosis	
Inattentive	51 (21%)
Hyperactive	9 (4%)
Combined	156 (66%)
Not Otherwise Specified	21 (9%)
Problematic Performance ¹	
Overall School Achievement	106 (45%)
Reading	89 (38%)
Writing	123 (52%)
Math	90 (38%)
Oppositional Defiant Disorder	45 (19%)
Treatment Acceptability Questionnaire, Parent Version (TAQ-P) (Mean (SD)) ²	
Medication	3.8 (1.3)
Behavior Therapy	4.5 (1.1)
Impairment Rating Scale, Parent Version (Mean (SD)) ³	
Relationship with Playmates	2.7 (2.0)
Relationship with Siblings	2.7 (2.1)
Relationship with Parents	2.6 (2.0)
Relationship with Family in General	2.9 (1.9)
Academic Progress	4.0 (1.9)

¹Problematic performance defined as receiving a rating of 3 (somewhat of a problem) or 4 (problematic) on Vanderbilt Performance questions²Treatment Acceptability Questionnaire, Parent Version: 8 items, response range 1 (strongly disagree)–6 (strongly agree)

³ Impairment Rating Scale-response range of 0 (no problem)-6 (extreme problem) for each item

Table 3

A. Factor Structures of Preference and Goal Scales, According to Exploratory Factor Analysis Medication Preference Scale				
Item	Factor Pattern Coefficients			
	1	2	3	4
	Acceptability	Feasibility	Stigma	Adverse Effects
1. Medication is a reasonable way to help child	0.79746 *	−0.00350	−0.01550	0.24443
2. Feel comfortable working with doctor to find right medicine	0.85607 *	0.01313	−0.06361	0.08357
3. Trust in doctor to treat ADHD with medicine	0.77601 *	−0.03221	0.09711	0.00814
4. Concerned about time to meet with doctor	−0.07931	0.71631 *	−0.00486	0.05709
5. Concerned about time to make sure child takes medication	0.09155	0.82813 *	0.05554	−0.03171
6. Concerned about time to monitor child's reaction to medication	0.03558	0.84237 *	0.04902	0.02915
7. Concerned about resources needed to cover cost of medication	−0.07059	0.47047 *	0.20175	0.09458
8. Afraid child will be considered a problem child	0.03582	0.09053	0.79052 *	0.06568
9. Afraid others will consider him/her a bad parent	−0.06243	0.11386	0.59507 *	0.05243
10. Child will be treated differently if takes medication	−0.04020	0.01261	0.90557 *	0.07330
11. Can get medication at a place where feels comfortable	0.42414 *	0.03434	−0.23483	−0.02970
12. Worried about reaction child might have to medication	−0.06037	0.02838	−0.02377	0.89959 *
13. Medication might change child's personality	0.12806	0.05413	0.24530	0.52740 *
14. Medication will improve child's behavior	0.78796 *	0.01228	0.00373	0.06989
15. Have support of others in giving child medication	0.67948 *	−0.03866	0.10442	−0.01781
16. Worried medication will be addictive	0.13297	0.05244	0.16446	0.44280 *
α coefficients	0.87	0.83	0.83	0.74

B. Factor Structures of Preference and Goal Scales, According to Exploratory Factor Analysis Behavior Therapy Preference Scale			
Item	Factor Pattern Coefficients		
	1	2	3
	Acceptability	Adverse Effects	Feasibility
1. Behavior therapy is a reasonable way to help child	0.69653 *	0.01327	−0.00663
2. Feel comfortable working with counselor/psychologist	0.88250 *	−0.01348	−0.00815
3. Trust in counselor/psychologist to help child	0.79028 *	−0.09639	0.09850
4. Concerned about time to meet with counselor to learn behavior therapy	0.00087	0.03636	0.84654 *
5. Concerned about time to work with child using behavior therapy	−0.02772	0.04497	0.85961 *
6. Concerned about resources needed to cover cost of behavior therapy	−0.03037	0.20402	0.40569 *
7. Afraid child will be considered a problem child	0.05312	0.64481 *	0.19403
8. Child will be treated differently if receives behavior therapy	0.04046	0.66175 *	0.14955

B. Factor Structures of Preference and Goal Scales, According to Exploratory Factor Analysis Behavior Therapy Preference Scale			
Item	Factor Pattern Coefficients		
	1	2	3
	Acceptability	Adverse Effects	Feasibility
9. Can receive behavior therapy at a place where feels comfortable	0.49415 *	0.05330	-0.01475
10. Worried about reaction child might have to behavior therapy	0.03351	0.72386 *	0.12712
11. Afraid child might react negatively to behavior therapy	0.04152	0.70119 *	0.06887
12. Behavior therapy will improve child's behavior	0.59969 *	-0.00716	-0.04758
13. Behavior therapy might change child's personality	-0.05722	0.61537 *	-0.05895
14. Have support of others in treating child with behavior therapy	0.50909 *	0.21259	-0.04186
15. Worried it will be hard to stop going to behavior therapy once start.	0.00083	0.37166	0.15343
α coefficients	0.82	0.83	0.76

C. Factor Structures of Preference and Goal Scales, According to Exploratory Factor Analysis Goals Scale			
Item	Factor Pattern Coefficients		
	1	2	3
	Academic Achievement	Behavioral Compliance	Interpersonal Relations
1. Stay out of trouble at school	0.11047	0.79607 *	-0.02295
2. Sit through meals more easily	0.03480	0.21954	0.33799
3. Be more caring toward adults in family	-0.09005	0.39471	0.44757 *
4. Complete schoolwork on time	0.76195 *	-0.05346	-0.01548
5. Be picked on less by other children	0.19645	0.05009	0.42395 *
6. Work better with teachers	0.35438	0.53072 *	0.08203
7. Follow rules at home	0.04207	0.61254 *	0.17409
8. Have fewer accidents that hurt	0.11730	0.26246	0.46600
9. Have more fun with other children	-0.02597	0.23468	0.73886 *
10. Focus better on work at school	0.71099 *	0.05608	-0.00564
11. Adults in family have more fun with child	0.07273	0.21331	0.52490 *
12. Take less time to complete homework	0.55957 *	-0.02488	0.01652
13. Make friends more easily	0.04346	-0.04026	0.81833 *
14. Get better grades	0.76514 *	0.10540	-0.01564
15. Complete chores with less difficulty	0.23050	0.26220	0.23201
16. Be better at following school rules.	0.02059	0.89041 *	-0.03564
17. Fall asleep more easily	0.01629	0.06700	0.33489
18. Get along better with other children in household	-0.07589	0.31567	0.53242 *
19. Argue less with other children	-0.04993	0.57707	0.40737
20. Learn more at school	0.68728 *	0.10994	0.10596
21. Have more confidence	0.43497	-0.13087	0.44958

C. Factor Structures of Preference and Goal Scales, According to Exploratory Factor Analysis Goals Scale			
Item	Factor Pattern Coefficients		
	1	2	3
	Academic Achievement	Behavioral Compliance	Interpersonal Relations
22. Care more about doing well in school	0.65253 *	0.30017	0.01841
23. Cooperate better with other children	−0.02167	0.54424	0.48900
α coefficients	0.86	0.86	0.83

* Items that were retained because they had factor loadings of 0.4 on only one factor and fit conceptually with the other items loading on that factor.

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Table 4

Average Item Ratings for the Preference and Goal Scales, Subscales, and for Each Item

	Mean Item Score (95% CI)
MEDICATION PREFERENCE SCALE:	
Overall scale	2.64 (2.55, 2.74)
<u>Factor 1: Acceptability</u>	2.54 (2.41, 2.66)
1. Medication is a reasonable way to help child	2.22 (2.06, 2.38)
2. Feel comfortable working with doctor to find right medicine	2.76 (2.60, 2.92)
3. Trust in doctor to treat ADHD with medicine	2.67 (2.51, 2.83)
4. Can get medication at a place where feels comfortable	2.78 (2.61, 2.95)
5. Medication will improve child's behavior	2.38 (2.24, 2.53)
6. Have support of others in giving child medication	2.42 (2.24, 2.59)
<u>Factor 2: Feasibility</u>	3.01 (2.88, 3.15)
1. Concerned about time to meet with doctor	3.21 (3.06, 3.36)
2. Concerned about time to make sure child takes medication	3.23 (3.07, 3.38)
3. Concerned about time to monitor child's reaction to medication	2.85 (2.68, 3.02)
4. Concerned about resources needed to cover cost of medication	2.78 (2.60, 2.96)
<u>Factor 3: Stigma</u>	3.06 (2.93, 3.19)
1. Afraid child will be considered a problem child	2.88 (2.72, 3.04)
2. Afraid others will consider him/her a bad parent	3.27 (3.14, 3.41)
3. Child will be treated differently if takes medication	3.02 (2.87, 3.16)
<u>Factor 4: Adverse Effects</u>	1.87 (1.73, 2.02)
1. Worried about reaction child might have to medication	1.43 (1.26, 1.60)
2. Medication might change child's personality	1.97 (1.79, 2.14)
3. Worried medication will be addictive	2.22 (2.02, 2.40)
BEHAVIOR THERAPY PREFERENCE SCALE:	
Overall scale	2.93 (2.86, 3.01)
<u>Factor 1: Acceptability</u>	2.99 (2.90, 3.08)
1. Behavior therapy is a reasonable way to help child	2.98 (2.86, 3.10)
2. Feel comfortable working with counselor/psychologist	3.20 (3.08, 3.32)
3. Trust in counselor/psychologist to help child	3.12 (3.00, 3.23)
4. Can receive behavior therapy at a place where feels comfortable	2.90 (2.76, 3.03)
5. Behavior therapy will improve child's behavior	2.77 (2.64, 2.90)
6. Have support of others in treating child with behavior therapy	2.97 (2.82, 3.12)
<u>Factor 2: Adverse Effects</u>	3.06 (2.94, 3.17)
1. Afraid child will be considered a problem child	3.20 (3.06, 3.34)
2. Child will be treated differently if receives behavior therapy	3.11 (2.97, 3.24)
3. Worried about reaction child might have to behavior therapy	2.90 (2.74, 3.06)
4. Afraid child might react negatively to behavior therapy	3.16 (3.01, 2.30)
5. Behavior therapy might change child's personality	2.93 (2.77, 3.10)
<u>Factor 3: Feasibility</u>	2.61 (2.47, 2.74)

	Mean Item Score (95% CI)
1. Concerned about time to meet with counselor to learn behavior therapy	2.60 (2.45, 2.76)
2. Concerned about time to work with child using behavior therapy	2.77 (2.62, 2.92)
3. Concerned about resources needed to cover cost of behavior therapy	2.44 (2.26, 2.63)
GOALS SCALE:	
Overall scale	1.85 (1.74, 1.96)
<u>Factor 1: Academic Achievement</u>	2.40 (2.26, 2.54)
1. Complete schoolwork on time	2.64 (2.46, 2.82)
2. Focus better on work at school	3.17 (3.02, 3.32)
3. Take less time to complete homework	2.08 (1.90, 2.27)
4. Get better grades	2.04 (1.84, 2.24)
5. Learn more at school	2.24 (2.04, 2.43)
6. Care more about doing well in school	2.24 (2.04, 2.44)
<u>Factor 2: Behavioral Compliance</u>	2.20 (2.04, 2.36)
1. Stay out of trouble at school	1.96 (1.75, 2.17)
2. Work better with teachers	2.16 (1.97, 2.34)
3. Follow rules at home	2.53 (2.35, 2.70)
4. Be better at following school rules.	2.16 (1.97, 2.36)
<u>Factor 3: Interpersonal Relationships</u>	1.25 (1.11, 1.38)
1. Be more caring toward adults in family	1.15 (0.96, 1.33)
2. Be picked on less by other children	0.98 (0.81, 1.15)
3. Have more fun with other children	1.39 (1.20, 1.58)
4. Adults in family have more fun with child	1.22 (1.03, 1.40)
5. Make friends more easily	1.24 (1.06, 1.42)
6. Get along better with other children in household	1.51 (1.31, 1.71)

Table 5

Test-Retest Validity with 21 Subjects, 14 Days After Enrollment

	Intraclass Correlation Coefficient^I
Medication Preferences-Overall Scale	0.86
Medication Acceptability	0.72
Medication Feasibility	0.52
Medication Stigma	0.79
Medication Adverse Effects	0.71
Behavior Therapy Preferences-Overall Scale	0.86
Behavior Therapy Acceptability	0.65
Behavior Therapy Adverse Effects	0.82
Behavior Therapy Feasibility	0.72
Goals-Overall Scale	0.90
Goals Academic Achievement	0.89
Goals Behavioral Compliance	0.78
Goals Interpersonal Relationships	0.95

^I Interclass correlation coefficient: 0.80 excellent agreement, 0.61-0.79 moderate agreement, 0.41–0.60 fair agreement

Table 6**Construct Validity of Preference Scales**

	On Treatment ¹ Mean Item Score (95% CI)	Not on Treatment ¹ Mean Item Score (95% CI)	p-value ²
Medication Behavior Therapy	3.01 (2.85, 3.16) 3.09 (2.92, 3.25)	2.43 (2.25, 2.61) 2.90 (2.76, 3.04)	<0.0001 0.09
	Late Stage of Decision Making ³ Mean Item Score (95% CI)	Early Stage of Decision Making ³ Mean Item Score (95% CI)	p-value ²
Medication Behavior Therapy:	2.83 (2.70, 2.95) 2.99 (2.88, 3.10)	2.42 (2.30, 2.55) 2.86 (2.76, 2.97)	<0.0001 0.1

¹Only children diagnosed >90 days prior to enrollment included in this analysis

²P-values calculated by linear regression comparing means between groups.

³Stage of decision making determined using the Ottawa Decision Toolkit item that reads: "In thinking about treating your child who has or may be diagnosed with ADHD, would you say you: 0-haven't begun to think about choices; 1-haven't begun to think about the choices, but are interested in doing so; 2-are considering options now; 3-are close to selecting an option; 4-have already made a decision, but are still willing to reconsider; 5-have already made a decision and are unlikely to change your mind." 0–2 defined as early, 3–5 defined as late.

Table 7

Construct Validity of Goal Scale

Goal Domain	Comparison Groups	Mean Item Average	p-value ¹
Academic Achievement	Problematic Overall School Performance ² Not Problematic	2.89 (2.72, 3.07) 1.98 (1.78, 2.17)	<0.0001
Behavioral Compliance	Combined ADHD Inattentive ADHD	2.61 (2.31, 2.90) 1.30 (0.99, 1.61)	<0.0001
Interpersonal Relationships	Oppositional Defiant Disorder Not ODD	1.87 (1.44, 2.31) 0.92 (0.73, 1.12)	<0.0001

¹ P-values calculated by linear regression

² Problematic performance defined as receiving a rating of 3 (somewhat of a problem) or 4 (problematic) on Vanderbilt Performance question