

Development of a Tool to Help Families Participate in ADHD Treatment Decision-Making

WHAT WE ASKED:

What is the best way to understand families' preferences and goals for ADHD treatment?

Attention Deficit-Hyperactivity Disorder (**ADHD**) affects more than 4 million children, and results in impaired academic performance, self-esteem, and interpersonal relationships. Several evidence-based treatment options exist, including **medication** and **behavior therapy**.

For both pediatric professionals and the public, ADHD treatment is **controversial and potentially stigmatizing**. Choosing the best treatment depends upon **families' beliefs, past experiences, concerns, and goals**. These preferences and goals are taken into account using a practice called **Shared Decision-Making**, a process in which families and clinicians partner together to reach decisions about medical care. However, before this study, there was no scientifically proven tool for families to identify and communicate about their ADHD treatment preferences and goals.

WHAT WE DID:

With input from families of children with ADHD, pediatricians, psychologists, and an ADHD advocacy group, we developed a questionnaire (***The ADHD Preference and Goal Instrument***) to help families: 1) identify their preferences and goals for ADHD treatment, and 2) share those preferences and goals with their medical providers.

The purpose of this tool is to focus ADHD treatment on what families want to achieve using the therapies they find acceptable. The Instrument includes a **medication preference survey, a behavior therapy preference survey, and a goal survey**. We tested the tool with 239 parents/legal guardians of children, aged 6-12, who had been diagnosed with ADHD in the past 18 months, and assessed its **reliability** and **scientific validity**.*

WHAT WE FOUND:

- **The ADHD Preference and Goal Instrument was successful** in helping families and clinicians decide on treatments that achieve families' goals and that respect their preferences about medication and behavior therapy.
 - The Instrument demonstrated **reliability**, meaning that families' responses were consistent when they repeated the questionnaire 1-2 weeks after taking it the first time.
 - Results from the survey were **scientifically valid**, consistent with what we expected based on our experience working with families.
 - **Families' preferences tended to align with their child's current therapy:** parents of children who were already on medication or receiving behavior therapy had greater preference for their respective treatment.
 - **Families' goals matched their children's identified needs:** parents of children with school problems had stronger academic goals; those dealing with behavior problems had stronger behavior goals; families with a child with Oppositional Defiant Disorder had stronger interpersonal goals.

WHAT IT MEANS:

- *The ADHD Preference and Goal Instrument* is the **first rigorously validated tool** to support the assessment of families' preferences and goals for ADHD treatment. It is a tool that can help providers meet national guidelines on shared decision-making.
- This Instrument offers a **model** for understanding how families think about and communicate preferences and goals **for a variety of pediatric chronic conditions**, like ADHD, which ultimately may improve treatment adherence and engagement.
- Based on the study's promising results, the research team is examining how the Instrument affects **ADHD outcomes, parent involvement in decision-making, treatment adherence and receipt, and engagement in care**, as well as the feasibility of using the tool in office settings and its acceptability to parents and clinicians.

*For detailed study methods, see the back of this sheet.

STUDY METHODS: Factor analysis was used to identify underlying themes (domains) that reflect how parents think about preferences and goals in ADHD. We calculated mean item ratings for each scale and domain, and used these ratings to assess validity. We compared responses to the *ADHD Preference and Goal Instrument* with two validated scales (the Treatment Acceptability Questionnaire and the Impairment Rating Scale) using Pearson correlation coefficients that measure agreement between responses. Test-retest reliability, a measure of agreement between initial and subsequent responses within a narrow period of time, was assessed by re-administering the survey to 21 parents 7-14 days after completion of initial study measures, and calculating intra-class correlation coefficients.

THE ADHD PREFERENCE AND GOAL INSTRUMENT:

The tool is made up of 3 components -

- **16-item Medication Preference scale** that assesses families' concerns about acceptability, feasibility, stigma, and side effects
- **14-item Behavior Therapy Preference scale** that assesses families' concerns about acceptability, feasibility, and adverse effects
- **16-item Goal scale** that assesses whether families prioritize the goals of improved academic achievement, improved behavior, and/or improved interpersonal relationships.

Sample Items (families rated their agreement with statements on a scale of 0 [agree not at all] to 4 [agree completely]):

- "Medication is a reasonable way to help my child."
- "I am worried about the reaction(s) my child might have to behavior therapy."
- "My child needs to be better at completing schoolwork on time."

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Further research forthcoming.

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