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Benefits and Barriers to Evidence-Based Behavioral Health Services for Children with ADHD in Georgia

Angie Snyder, MPH, PhD; Ann DiGirolamo, PhD, MPH; Amanda Martinez, MPH; Colleen Smith, MSW

RESEARCH OBJECTIVE
Findings from the 2010-11 National Survey of Children’s Health suggest that approximately 194,000 preschoolers had a current attention-deficit/hyperactivity disorder diagnosis (ADHD). Among preschoolers with special health care needs who had a diagnosis of ADHD, 53% were receiving behavioral therapy and 40% were taking medication for treatment; similar results were found with Medicaid claims data in Georgia. The American Academy of Pediatrics (AAP) recommends behavioral therapy as first-line treatment for young children with ADHD. Therefore, these findings suggest a misalignment between current practice and best practice for ADHD treatment. This project characterizes perceived benefits and barriers to receiving behavioral treatment among parents of children diagnosed with ADHD.

STUDY DESIGN
The project utilized qualitative methodology to obtain in-depth information on parental perceptions of barriers and benefits to behavioral treatment for young children with ADHD. A series of focus groups were conducted with parents of children diagnosed with ADHD. Transcribed data were analyzed for common themes delineating perceived benefits and barriers to receiving behavioral treatment for ADHD, along with key challenges experienced by parents in obtaining needed services for their child.

POPULATION STUDIED
Parents of children 2.7 years old with a diagnosis of ADHD (n=8) or who had a child diagnosed with ADHD in the last 5 years regardless of age (n=6) were recruited from urban areas in Georgia to participate in focus groups designed to better understand parents’ experiences obtaining needed services for ADHD.

PRINCIPAL FINDINGS
Perceived Barriers to Receiving Behavioral Treatment for ADHD

- Lack of knowledge of available treatment
- Lack of time for therapy
- Lack of access to services
- Cost, perceived stigma from others, and system barriers

- The medication just didn’t work.
- They didn’t communicate well with each other.
- My son doesn’t like the school medication.

- My child doesn’t like the medication.
- We tried everything and it just didn’t work.

Stigma/Attitude from Others

- Being a “bad parent,” avoidance by others, and system barriers

- Other parents are kind of like it’s contagious… around yours.”
- “It’s like you’re a bad parent… I don’t want my kid to come get her and they’re like, ‘You just need to talk with your daughter about this unacceptable behavior’…”
- “Other parents are kind of like it’s contagious… it’s like you’re a bad parent. I don’t want my kid around yours.”

Challenges with Medication

- Finding right medication/taking multiple crises, insurance coverage of brand name medications when generic brands are as effective
- Stigma/Attitudes from Others
- Perceived Barriers to Receiving Behavioral Treatment for ADHD
- Challenges with Medication
- General Challenges in Receiving Needed Services for ADHD

- “I have to hide food because if it’s there it’s gonna get eaten. I can’t even get homework done. So, there’s no way I’m gonna have time for our major therapy sessions.”
- “From Adderall to Methylphenidate to Clonidine… it’s been a nightmare. So long story short, he’s just finished kindergarten. We’ve had five suspensions in kindergarten.”
- “I have to hide food because if it’s there it’s gonna get eaten. I can’t keep anything.”

General Challenges in Receiving Needed Services for ADHD

- Lack of communication among providers working in isolation, lack of comprehensive approach and constant searching for right answer for child
- “I think the missing piece is the lack of collaborative care from the medical perspective. They’re all focused on what they know and their specialty. All of our children are complex children, there’s not one thing going on. Our frustration with the pediatrician is that while he is up on all the research on stimulants and non-stimulants, when we go in for a med check and there are other things going on…”
- “Stigma/Attitudes from Others
- Perceived Barriers to Receiving Behavioral Treatment for ADHD
- Challenges with Medication
- General Challenges in Receiving Needed Services for ADHD

- “Other parents are kind of like it’s contagious… other parents are kind of like it’s contagious… other parents are kind of like it’s contagious… other parents are kind of like it’s contagious…”
- “You either go online or you read or talk with parents and you hear something working and then you try that. Because you’re searching for the magic pill… those 50 things haven’t worked but I guess I try another 50 things. So you just keep trying.”

CONCLUSION
Despite clear recommendations by AAP to use behavioral therapy as first-line treatment for ADHD, parents in Georgia are still experiencing difficulties obtaining behavioral services when needed. Of key concern is a lack of coordinated care for children and factors such as cost and availability of behavioral treatment. Further, parents also identified a need to work with both the healthcare and education systems to increase their understanding of ADHD and the value of behavioral treatment.

IMPLICATIONS FOR POLICY OR PRACTICE
In order to increase the probability of best practice for addressing ADHD, the health care and educational systems should acknowledge the complexity of children with ADHD who often have multiple diagnoses, and the important role that successful care coordination can play. Barriers such as cost and availability of quality treatment should also be addressed.

For more information, please contact the Georgia Health Policy Center at 404.413.0314 or visit us online at www.ghpc.gsu.edu