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Benefits and Barriers to evidence-based behavioral health Services for Children with ADHD in Georgia

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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

Parents noted exploring a variety of interventions and services to address their children's ADHD behavior, including behavioral therapy, medication treatment and alternative therapies such as diet/nutrition, physical activity and increased sleep. They noted a constant search for answers and ways to manage their child's condition. In addition, several key themes emerged in the areas of Stigma/Attitudes from Others, Perceived Barriers to Receiving Behavioral Treatment for ADHD, Challenges with Medication, and General Challenges to Receiving Needed Services for ADHD.

Stigma/Attitude from Others

Being a "bad parent", avoidance by others, and staying away from public places

"It's hard because your child doesn't wear a stamp, 'Oh, I have ADHD. Please be understanding.' And they just think, 'Oh God. What's wrong with you, and what's wrong with your child?'"

"My coworkers say, 'Oh my goodness.' They hear people calling me at work and asking me to come get her and they're like, 'You just need to spank her.'"

"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.'"

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 evaluator put ADHD/ODD. She did not tell me to follow up with her or where to go. I got the results but did not know where to go. So I had to do the search."

"This is a 12 hour pill. She gets it at 7 in the morning. It is gone by 5. Gone. I can't even get homework done. So, there's no way I'm gonna have time for our major therapy sessions."

"When I was looking for someone to assess my son, one psychologist told me that for insurance he had an appointment 2-3 months in advance. But if I was paying cash, he could see me the next day."

"When we started, he got meds, and we were seeing the psychologist. The pediatrician's office was like, 'Oh well, if he's on meds, you don't need to see anybody.'"

"With my daughter, no behavioral therapy. Just suspending and 'You need to talk with your daughter about this unacceptable behavior'…she was treated as the bad kid…no type of behavioral therapy. I don't think the teacher understood."

Challenges with Medication

Finding right medication/trying multiple ones, insurance coverage of brand name medications when generic brands are less effective, rebound in the evenings, and side effects (trouble sleeping, weight gain, weight loss

"From Adderall to Metadate to Ritalin to Clonidine…it's been a nightmare. So long story short, he's just finished kindergarten. We've had five suspensions in kindergarten."

"We're in this big battle with both Focalin and Intuniv because there are generics available for both…to get the insurance company to cover the name brand…they don't want to do it."

"…the evenings with him are lots of screaming…you would think I was murdering my children."

"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 answers/need for advocacy

"I think the missing piece is nobody takes a comprehensive look…from the medical perspective. They're all focused on what they know and their specialty. All 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…he says, 'But is the attention better during the day? This is an attention problem.' And it was like he had blinders on."

"You either go online or you read or talk with parents and you hear something's working and then you try that. Because you're searching for the magic pill…these 50 things haven't worked but I guess I'll 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

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