Contrasting Parents' and Pediatricians' Perspectives on Shared Decision-Making in ADHD

WHAT'S KNOWN ON THIS SUBJECT: Shared decision-making (SDM) is recommended when multiple evidence-based treatments exist and families value options differently. Although national guidelines prioritize SDM in attention-deficit/hyperactivity disorder, little is known regarding how parents and clinicians understand and implement SDM in practice.

WHAT THIS STUDY ADDS: We found that practical barriers limit the consideration of evidence-based options in SDM, key participants often are excluded from the process, and, although parents and clinicians view SDM favorably, they understand SDM differently. Implications for clinical practice are discussed.

abstract

OBJECTIVE: The goal was to compare how parents and clinicians understand shared decision-making (SDM) in attention-deficit/hyperactivity disorder (ADHD), a prototype for SDM in pediatrics.

METHODS: We conducted semi-structured interviews with 60 parents of children 6 to 12 years of age with ADHD (50% black and 43% college educated) and 30 primary care clinicians with varying experience. Open-ended interviews explored how pediatric clinicians and parents understood SDM in ADHD. Interviews were taped, transcribed, and then coded. Data were analyzed by using a modified grounded theory approach.

RESULTS: Parents and clinicians both viewed SDM favorably. However, parents described SDM as a partnership between equals, with physicians providing medical expertise and the family contributing in-depth knowledge of the child. In contrast, clinicians understood SDM as a means to encourage families to accept clinicians' preferred treatment. These findings affected care because parents mistrusted clinicians whose presentation they perceived as biased. Both groups discussed how real-world barriers limit the consideration of evidence-based options, and they emphasized the importance of engaging professionals, family members, and/or friends in SDM. Although primary themes did not differ according to race, white parents more commonly received support from medical professionals in their social networks.

CONCLUSIONS: Despite national guidelines prioritizing SDM in ADHD, challenges to implementing the process persist. Results suggest that, to support SDM in ADHD, modifications are needed at the practice and policy levels, including clinician training, incorporation of decision aids and improved strategies to facilitate communication, and efforts to ensure that evidence-based treatment is accessible. *Pediatrics* 2011;127:e188–e196

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KEY WORDS

shared decision-making, attention-deficit/hyperactivity disorder

ABBREVIATIONS

ADHD—attention-deficit/hyperactivity disorder

SDM—shared decision-making

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Shared decision-making (SDM) is a technique in which families and clinicians jointly participate in decisions, exchange information and preferences, and decide on a treatment plan.[1,2] This process is particularly helpful when clinical situations have multiple evidence-based options and when variation exists in how families weigh their risks and benefits.[3] Research on the comparative effectiveness of SDM has been prioritized by the Institute of Medicine.[4] Although randomized trials demonstrated the efficacy of SDM in improving decision quality and reducing the overuse of options that patients do not value, research on SDM has focused on adult health care.[5,6] Findings in pediatrics suggest that parents are more satisfied when they participate in making clinical decisions[7]; however, little is known about how parents and pediatric clinicians approach SDM and how best to implement this process in pediatric practice.[8]

To address this knowledge gap, we conducted a qualitative study to compare the perspectives of parents and pediatric clinicians regarding SDM in attention-deficit/hyperactivity disorder (ADHD). ADHD is an ideal prototype for the study of SDM in pediatrics for several reasons, as follows: there are multiple evidence-based treatment options, including behavior therapy and medication,[9,10] treatment is preference sensitive and families often are uncertain regarding their choices,[11] the condition is common and affects the health and functioning of families, schools, and communities,[12,13] and adherence mediates the effectiveness of treatment.[14] In addition, national guidelines on ADHD treatment prioritize family involvement in decision-making.[10] An improved understanding of parents' and clinicians' perspectives on SDM would provide a foundation to support this process in pediatric practice.

METHODS

Setting

This study was conducted within The Children's Hospital of Philadelphia Pediatric Research Consortium, a multistate, hospital-owned, primary care network including >235 000 children. Study practices included 4 urban teaching practices, in which <35% of patients had private insurance, and 17 primarily suburban practices not involved in resident teaching, in which >80% of children were privately insured. Parent participants also were recruited through a posting on the Web site of the Children and Adults With Attention Deficit/Hyperactivity Disorder, an advocacy group for affected families. The Children's Hospital of Philadelphia institutional review board approved the study. All participants provided written consent.

Study Design and Patient Population

We conducted open-ended, semistructured, in-depth interviews with 60 parents of children 6 and 12 years of age with ADHD and 30 pediatricians, between March 2008 and March 2009. Clinicians were invited by the research team to participate in a study of treatment decisions in ADHD, and eligible parents were referred to the study by their clinicians or through the Web site of the Children and Adults With Attention Deficit/Hyperactivity Disorder. All parents who contacted the study team to express interest in participating and who met the eligibility criteria were enrolled. All invited clinicians agreed to participate. Fifty-one parent participants were enrolled through The Children's Hospital of Philadelphia network, and 9 parent subjects were enrolled through the Internet site. The 6- to 12-year age range was chosen to match the age at which most children are diagnosed as having ADHD and the target population of national ADHD guidelines.[10,12] Because perceptions of ADHD have been found to differ between black and white parents, purposeful sampling was used to achieve balanced samples of parents from these groups.[15–17] Similarly, we purposively sampled clinicians with varying levels of experience, because research suggests that younger age is associated with a more-participatory decision-making style for ADHD.[18]

Data Collection

Through a detailed review of the relevant literature and consultation with outside experts, we developed an interview guide to elicit parents' and clinicians' experiences, attitudes, and beliefs regarding treatment decisions for ADHD. Questions were primarily open-ended, and no leading questions were used. The interview guide is available from the authors on request. Parents and clinicians were prompted to discuss their actual and preferred involvement in making these decisions. Before the start of the study, each interviewer was trained by a member of the study team with extensive experience in qualitative methods (Dr Barg), who then observed each interviewer conduct mock interviews. The team met biweekly throughout the study, to ensure interview consistency and data quality and to modify the interview guide as emerging themes developed. We also collected demographic data on parents and clinicians. Interviews were recorded digitally, transcribed, and entered into NVivo 8.0 software (QSR International, Melbourne, Australia) for analysis.

Data Analyses

We used a modified grounded theory approach to code the interviews inductively, without using an a priori set of codes.[19] Three research team members read the first 4 interviews, and, after developing an initial coding scheme, independently coded each transcript, assigning codes to specific comments in each transcript. By using an iterative process, we regularly reviewed codes, identified emerging themes, and resolved any discrepancies through consensus. With the use of NVivo, each transcript was linked to participants' demographic data. NVivo enables users to query the transcript database to generate lists of verbatim comments associated with particular codes. After all transcripts were coded, a fourth study member not involved in data collection reviewed each list of comments and collaborated with the team to identify dominant themes. Representative verbatim comments were selected for presentation.

RESULTS

Study Groups

Sixty parents of children with ADHD and 30 pediatricians were enrolled in the study. Demographic characteristics of participants are presented in Table 1. We identified 3 primary themes: (1) parents and clinicians conceptualize SDM differently; (2) parents' and clinicians' perceptions regarding barriers to treatment implementation limit consideration of evidence-based options; and (3) SDM extends beyond the parent-clinician dyad. We provide representative quotations for these themes below, with additional supporting quotations in Table 2. Although we purposively sampled to achieve balances of black and white parents and clinicians' experience, we did not observe patterned responses on the basis of parents' race or clinicians' experience. In our sample, children were not described as central to SDM because they were considered to be too young; however, parents indicated that, as children mature, they should play a growing role in SDM.

TABLE 1 Study Participant Characteristics

	n (%)
Parents (*N* = 60)	
Race	
Black	30 (50)
White	27 (45)
Other	3 (5)
Education	
High school diploma or less	20 (33)
Associate degree	7 (12)
Some college	13 (21)
Bachelor's degree	10 (17)
Master's degree or professional degree	10 (17)
Income	
Lower ($0–$32 999)	23 (38)
Middle ($33 000–$54 999)	13 (22)
Higher ($55 000 or more)	24 (40)
Relationship to child	
Mother	48 (80)
Father	4 (7)
Grandfather	3 (5)
Other legal guardian	5 (8)
Clinicians (*N* = 30)	
Race	
Black	2 (7)
White	25 (83)
Other	3 (10)
Gender	
Female	20 (67)
Male	10 (33)
Practice setting	
Urban resident teaching practices	14 (47)
Other practices (primarily suburban)	16 (53)
Time in practice (after training)	
<10 y	5 (17)
10–20 y	14 (47)
>20 y	11 (36)

Parents and Clinicians Conceptualize SDM Differently

Parents View SDM as Equal Partnership

Parents conceptualized SDM as an equal partnership, with parents and clinicians contributing distinct but valuable perspectives. One urban black mother described, "I like the 50–50 [approach] because it's my practicality and your knowledge . . . when it meshes together it becomes complete." Parents valued clinicians' medical expertise, as another urban black mother noted, "[Doctors] know more . . . than I would know. . . . I don't have a doctor degree." However, parents thought that their own lived experience yielded useful information for decision-making. One suburban white mother said, "I think parents know their kids a little bit better than a pediatrician that might see the child . . . once a year."

Parents emphasized the importance of clinicians providing information regarding all treatment options. They reacted negatively to doctors who "pushed" medication without offering a balanced presentation of alternatives. One suburban white mother said, "I'm not sure if it's shared decision-making. It feels like it's [the doctor] telling me what the next step is." Another suburban white mother remarked, "My frustration is that [the doctor] is very focused on medication and I was thinking there's got to be something else." In contrast, an urban black mother relayed a positive experience, saying, "They didn't try to push anything on me. They allowed me to go [through] the process." Parents trusted clinicians who invited them to take part in decision-making and those who conveyed respect for parents' views by "listening first."

Nearly all parents in our study reported that they wanted to participate in the treatment decision-making process. However, this often meant participating in some but not all aspects of SDM (Table 3). For example, some parents wanted to exchange information and treatment preferences but ultimately wanted the clinician to make the final decision "for" them. This process also was a reflection of the trust parents had in their clinicians. For example, one mother said, "I'm going to trust [my doctor] enough to make the right decision for me."

Clinicians View SDM as Way to Get Parents to Comply With Clinicians' Recommended Treatment

Although clinicians, like parents, were receptive to SDM, 22 (73%) of 30 clini-

TABLE 2 Themes Identified From Individual Interviews

Theme	Parents' Comments	Clinicians' Comments
Clinicians and parents conceptualize SDM differently		
	"Shared decision-making [is] not [the doctor] saying, 'This is what you have to do.' It's a conversation back and forth, you know questions, finding out information, is this the best thing for [my child] . . . it's a 'we' thing" (urban black mother) "[The doctors] draw out ideas and [my child] and I decide whether those ideas work for her" (suburban white mother) "It would have been nice to be given some other options and to know that there's something more than just taking pills" (suburban white mother)	"For compliance [parents] have to be part of the team" (suburban practice, 11 y of experience) "So a lot of times I, you know, convert parents to thinking of it in a different way, that they're not being weak by giving the medication, they're being proactive and giving their child the privilege of functioning well and succeeding, so I do a lot of that kind of stuff" (suburban practice, 22 y of experience) "I'm convinced that it's like diabetes, if you have the problem, you need medication to be properly treated" (suburban practice, 21 y of experience) "But I think to maximize the chances that the family's going to go along with what you think, you have to show the family that you spent the time and reviewed . . . the surveys and evaluations and discussed the families' thoughts and biases and what the family sees at home and how they interpret things and what their wishes are" (urban practice, 10 y of experience)
Parents' and clinicians' perceptions about real-world barriers limit consideration of evidence-based options		
Insurance	"I called the insurance company and I said, 'Do I get reimbursed for something?' And they said no. You know, you could fight it but good luck, because you won't get anything" (urban black mother) What prevented you from being able to see the therapist? "Insurance. Because [the child] has [name of insurance], but they only pay for her to see [the therapist] like 3 times a year, and I don't feel that's enough" (suburban white mother)	"It's very, very hard, I think, for families to get into those kinds of therapeutic relationships with psychologists or behavior psychologists, just because their insurance either limits who they can see or limits how many times they can see them, you know?" (urban practice, 12 y of experience) "Because there are not psychiatrists out there for me to refer them to within their insurance, so it's a hard decision for me to make. Sometimes I tell the patient I can't help you" (suburban practice, 21 y of experience) "So we're sort of limited between a handful of medicines so with treatment and medication, I don't really—there's not much I can do with that because you choose whatever their insurance will cover" (suburban practice, 16 y of experience)
Cost of care	"Basically, after I got the call [confirming the diagnosis], we looked up everything and there are other [treatments] but . . . you know, with the situation we're in we can't afford those things, so she's on the medication" (urban white mother) "I did find a place that offers different types of tutoring services and one is a coach where they would go with the child to school. . . . So I found the service, but it's just the matter of the cost, because they are expensive" (urban black mother)	"You can make a list of all the things [parents] should be doing, but it's really hard to get them to get those services" (suburban practice, 12 y of experience) "When we have families that can't even pay their bills every week, how are they going to have a $300.00 bill or a $200.00 an hour bill [for mental health services]? It's not going to happen" (suburban practice, 21 y of experience) "It gets prohibitory financially for some parents because of copays and insurance issues and that kind of thing. And to me that's something that shouldn't be but is the biggest glitch" (suburban practice, 28 y of experience)
Time	"I've just been getting the runaround. I've been trying to get a second consultation for a year and a half. . . . It's just frustrating, because you trying to do what's best for your child, but the world isn't letting you" (urban black mother) "I know I have to work and it's not easy to get the medicine, because I got to sit and wait for the doctor to call it in or I got to go get it. And that's complicated, because of where I live" (urban black mother)	"I think the other thing is just the easier access to mental health services. It's very difficult going through insurers, very difficult with time waits, and just difficult with some medications getting them preapproved. I mean there are just a lot of obstacles along the way" (suburban practice, 28 y of experience)

TABLE 2 Continued

Theme	Parents' Comments	Clinicians' Comments
Parents and clinicians describe SDM as a process that extends beyond the parent-clinician dyad		
Family members	"I mean I had so many different, people told me so many different things [about medication], it was confusing. And it was scary" (urban black mother) "Nobody was pushing the medication. His grandpop was against the medication, his dad was against the medication" (urban black mother)	"A lot of moms will come in with, 'Grandma said don't give him this medication. I can't put him on this medication.' And, you know, it takes a lot of discussion to try to get past that" (suburban practice, 12 y of experience) "I think parents do trust family members, friends that they know and trust can often give them a lot of valuable information, sort of subjective information" (suburban practice, 10 y of experience)
Professionals	"I listened to what the doctors had to say, the social worker . . . I talked to my family, they're involved" (urban black mother)	"We need to have support from psychologists and psychiatrists. We need to have access to that because that's such an important part of it" (suburban practice, 25 y of experience) "But I think mostly the access to other mental health providers and also the communication with schools [is lacking]. That is definitely a missing piece for me . . . contact with teachers" (urban practice, 13 y of experience)
Medical contacts	"I'm going to listen to what the doctor says and take his input. But then I'm going to get on my cell phone on the way home and call my cousin who's one of my best friends, a family practitioner, I run it all by her. So I'm taking what the doctor says and I'm researching after that" (suburban white mother) "My best friend's a pharmacist and my sister-in-law's a doctor as well, so I just talk to them" (suburban white mother)	

TABLE 3 Components of SDM[1]

Parents are involved with clinicians in the treatment decision-making process.
Parents and clinicians share information.
Parents and clinicians express treatment preferences.
Treatment decisions that are agreeable to both parties are made.

cians described SDM as a process of engaging parents to convince them to accept the clinicians' preferred option. One clinician noted, "I try to . . . talk them into my [treatment preference] . . . to persuade them of why I think my decision is going to help their child more." Rather than first exchanging information and then sharing treatment preferences, as is typical in SDM, clinicians often reversed the order of these steps. This approach reflects clinicians' use of information exchange to influence parents' choices.

Clinicians perceived that their role included determining how much families wanted to share responsibility for decision-making. For example, one clinician said he "[tries] to figure out how much do they want you to just decide and how much do they want to discuss and how much do they already have an idea." Eight clinicians (27%) in this sample did perceive SDM as a more-equal partnership. As one said, "I see it as much more of a partnership than most [clinicians]. . . . I'm a firm believer in really involving the parents in these decisions."

Parents' and Clinicians' Perceptions of Real-World Barriers Limit Consideration of Evidence-Based Options

Barriers Identified by Parents

When asked about SDM, parents consistently emphasized perceived barriers to implementing their treatment of choice. Parents focused on practical barriers they had already faced in accessing health care for their children, which informed their approach to making prospective decisions. These barriers included limited insurance coverage and consequent out-of-pocket costs and the time required to schedule and to attend doctor's appointments. Eighteen parents (30%) described making treatment choices on the basis of insurance coverage rather than effectiveness. Even with coverage, copays represented a burden for many families. One urban black mother described, "If it's medication, that's $15 every time we need to get it refilled." One higher-income, suburban, white mother decided to decrease her children's dosages because of the cost, saying, "I have 2 boys on ADHD medicine and it's $45 a month per prescription, so it's $90 a month for their medicines." Another prevalent barrier was the time required to implement and to optimize treatment. One mother, when discussing her difficulties managing her son's new medication, said, "Well, last year was pretty rough. I missed a lot of days from work."

Barriers Identified by Clinicians

Clinicians were aware of the barriers that families faced in navigating the health care system, which informed how they presented treatment options to families. In particular, they focused on the limited availability of affordable behavior therapy. One clinician remarked, "Very few of our patients with ADHD have insurance such that they can get therapy." In addition, clinicians noted that the quality of care often varied depending on families' income, "The families who have money will go to private counselors and get good counseling and be happy. The families who have to rely on their insurance are generally frustrated." Clinicians perceived that the likelihood of patients accessing quality behavioral therapy was poor, whereas medication treatment was more-readily available. Given this constraint, presenting medication as the preferred option was a logical choice.

Parents and Clinicians Describe SDM as Process That Extends Beyond Parent-Clinician Dyad

Parents' Social Networks Influence Decision-making

Parents and clinicians both consulted individuals beyond the parent-clinician dyad in the decision-making process. These individuals helped shape parents' perspectives but were not present during the clinical encounter. Parents often sought advice from friends and family who worked in the health professions. They used those trusted contacts as an informal "second opinion." A suburban white mother described, "I have a niece who's within the psychology field. So I'll rely on her to confirm whether I should or should not be alarmed at what issues [the doctor] might be presenting." Of note, nearly 3 times as many white parents as black parents reported conferring with medical contacts within their social networks.

Although parents' social networks often provided support, family members and friends, especially of black parents, sometimes presented obstacles to treatment decisions. One urban black mother described her sister's response to ADHD medication, "And my sister, she really freaked out. She was saying, 'why don't you just go ahead and buy him some crack?' " Another urban black mother said, "I would talk to family members and friends about medication and they were totally against it." Parental disagreement also complicated the decision-making process. A suburban white mother said, "I feel sorry for [my daughter] because I feel like she's stuck between my husband and I who . . . have different views regarding how she should be treated."

Clinicians Value Input From Other Professionals

For clinicians, key stakeholders in the decision-making process included specialists, such as therapists or psychiatrists, and teachers. However, logistic challenges limited clinicians' ability to consult with these professionals. One clinician explained, "The kids come here, but they're really spending their time elsewhere and [we need] more communication with the schools." Nearly one-half of the clinicians lamented their difficulties coordinating with other specialists, as one clinician said, "The therapist . . . almost never calls us. . . . Communication is poor. . . . Without that piece you're kind of working in the void." Another clinician described his efforts to engage other involved parties, saying, "I'm making phone calls on the way home at night, I'm making phone calls at 7:00 in the morning . . . because I don't have the time [at work] . . . and I'm talking to teachers, counselors, psychologists."

DISCUSSION

This study was conducted to compare the perspectives of parents and pediatric clinicians regarding SDM, a central component of guideline-based ADHD care and an approach applicable to many childhood conditions.[10] We found that, although parents and clinicians shared favorable views of the process, they understood SDM differently and implemented the process incompletely. Instead of acquainting families with all options first, pediatric clinicians in our study often presented information to persuade families to accept their preferred treatment. In contrast, and consistent with findings in other pediatric settings, we found that families desired comprehensive, unbiased information before decision-making, even if they ultimately delegated responsibility for the decision to the clinician.[20]

Because previous work demonstrated that families have considerable distrust of those treating ADHD,[15,21] as well as a hesitancy to ask about risks and benefits of treatments for various acute conditions,[22,23] and our findings suggest that a biased presentation of options compromises trust, approaches are needed to help clinicians communicate information regarding alternatives more effectively. Pediatric clinicians may benefit from training in SDM, which has proven effective in improving outcomes for children with behavior problems.[24] In addition, our results suggest that families and clinicians may benefit from the use of decisions aids, standardized and validated tools[20,25,26] to help families learn about the risks and benefits of treatment and to consider decisions in the context of their personal values.[5] Because use of these tools is limited in pediatrics,[20] the development and evaluation of approaches for implementing decision aids in pediatrics, as has been performed in the adult setting, is warranted.[27,28]

Our results also highlight the extent to which practical considerations constrain SDM for ADHD. Although barriers to care are known to affect treatment for behavioral conditions, especially among poor patients,[29,30] our results indicate that issues of cost, insurance coverage, and time limitations often prevent both poor and middle class families from considering scientifically proven options. In addition to affecting receipt of treatment,[31–33] we found that these barriers influence how clinicians present options to families. Our findings suggest the importance of efforts to help clinicians and parents weigh practical considerations in SDM, which are not traditionally the primary focus of decision aids.[25] This is especially important for chronic conditions such as ADHD, for which decisions are revisited over time as families acquire real-world experience with treatment.[34] In this context, SDM is likely to benefit from efforts to promote care coordination that help families mitigate barriers to receiving their preferred treatment,[35] as well as policy work to improve access to mental health services.[36]

Although much of the literature on SDM has focused on doctor-patient communication, SDM in ADHD extends beyond this dyad. Building on previous work that characterized the influence of social networks on families with ADHD[37] and the difficulties of clinicians in communicating with other professionals to coordinate care,[31] our findings underscore the often-central role of extended-family members, friends, and professionals from the school and mental health system in SDM. However, they rarely are active participants in the medical encounter. Further research is needed to understand how to engage actively in the decision-making process participants from multiple settings and how to address sometimes-unfounded but strongly held concerns about treatment options. With appropriate privacy protection, asynchronous communication through e-mail or Internet-based portals, approaches that have proven acceptable for families and time-saving for clinicians,[38–40] might be an important strategy to achieve this goal.

Given known disparities in care,[17,32,41] we purposively sampled even numbers of black and white participants, to understand how perspectives on SDM varied among groups. We found that views of SDM were similar for black and white parents. However, consistent with previous studies that identified greater ADHD information needs among black families,[17] our results indicated that black participants might not have benefited from contacts with health professionals within their social networks to the extent that white participants did. One strategy to address this gap is to recruit black students into the health professions, an approach that also may address broader health disparities.[42] In addition, these findings suggest that, although similar approaches to SDM may be effective across groups, the presentation of information may need to be tailored. Black parents, especially those whose friends and family members express concerns regarding treatment more strongly, may benefit from additional support from clinicians or referral to community groups.

This study had several limitations. We elicited parents' and clinicians' perceptions of SDM but did not confirm that perceptions matched actual patterns of decision-making and receipt of health services. Participants were primarily from 1 health system, and results might not be generalizable to all settings. Because most participants were recruited through a pediatric primary care network, views of families not using primary care might not have been captured. However, our goal was to explore perspectives on SDM in primary care, which made this setting appropriate for our study. In addition, the perspectives of clinicians and parents who participated might differ from the perspectives of those who did not volunteer. Our study was designed to explore how parents and clinicians understand SDM in ADHD. Although themes seem relevant to multiple chronic pediatric conditions, additional study will be needed to establish whether perspectives differ across conditions.

CONCLUSIONS

Despite national guidelines prioritizing SDM in ADHD, challenges to implementation include differing interpretations of SDM between parents and clinicians, perceived barriers to the use of evidence-based treatments, and difficulties involving key participants. Results suggest that, to realize the promise of SDM in pediatrics, modifications are needed at the practice and policy levels, including clinician training, incorporation of decision aids and improved strategies to facilitate communication, and efforts to ensure that evidence-based treatment is accessible.

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