ARTICLE

Physicians' Shared Decision-Making Behaviors in Attention-Deficit/Hyperactivity Disorder Care

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Objectives: To describe the amount of shared decision-making (SDM) behavior exhibited during treatment-planning encounters for children newly diagnosed as having attention-deficit/hyperactivity disorder and to explore relationships between participant characteristics and the amount of SDM.

Design: Prospective cohort study.

Setting: Seven community-based primary care pediatric practices in the Cincinnati, Ohio; northern Kentucky; and southeast Indiana regions from October 5, 2009, through August 9, 2010.

Participants: Ten pediatricians and 26 families with a 6- to 10-year-old child newly diagnosed as having attention-deficit/hyperactivity disorder.

Outcome Measure: The amount of SDM behavior exhibited during videorecorded encounters, as coded by 2 independent raters using the validated Observing Patient Involvement (OPTION) scale, which was adapted for use in pediatric settings and produces a score ranging from 0 (no parental involvement) to 100 (maximal parental involvement).

Results: Treatment decisions focused on initiation of medication treatment. The mean (SD) total OPTION score was 28.5 (11.7). More SDM was observed during encounters involving families with white vs nonwhite children (adjusted mean difference score, 14.9; 95% confidence interval [CI], 10.2-19.6; $P<.001$), private vs public health insurance coverage (adjusted mean difference score, 15.1; 11.2-19.0; $P<.001$), mothers with at least some college education vs high school graduate or less (adjusted mean difference score, 12.3; 7.2-17.4; $P<.001$), and parents who did not screen positive for serious mental illness vs those who did (adjusted mean difference score, 15.0; 11.9-18.1; $P<.001$).

Conclusions: Low levels of SDM were observed. Exploratory analyses identified potential disparities and barriers. Interventions may be needed to foster SDM with all parents, especially those of nonwhite race, of lower socioeconomic status, of lower educational level, and with serious mental illness.

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The Institute of Medicine and the American Academy of Pediatrics recognize shared decision-making (SDM) as a process that holds potential to improve the quality of health care.[1-3] Shared decision-making involves health care professionals communicating information regarding treatment options and patients and parents communicating the personal value they place on benefits vs harms so that agreement on the best strategy for the individual patient can be reached.[4] Treatment decisions with 2 or more medically reasonable alternatives are conducive to an SDM process. One such decision that is common to pediatric primary care settings[5] is treatment of attention-deficit/hyperactivity disorder (ADHD). Convincing evidence exists for 3 treatment strategies (eg, behavioral therapy only, stimulant medication only, or both). However, the potential benefits (eg, ADHD symptom reduction) and harms (eg, adverse effects and costs) differ among these options.[6] As a result, ADHD treatment guidelines recognize the importance of developing a treatment plan that takes into account family goals, preferences, cultural values, and concerns.[7,8]

Surprisingly little is known about SDM in pediatrics, especially in the context of chronic conditions such as ADHD. What is known is based on physician or parent report. Most primary care physicians in 1 study[9] reported involving parents of children with ADHD in decision making. Similarly, in 2 large surveys[10,11] parents of children with ADHD reported that their child's

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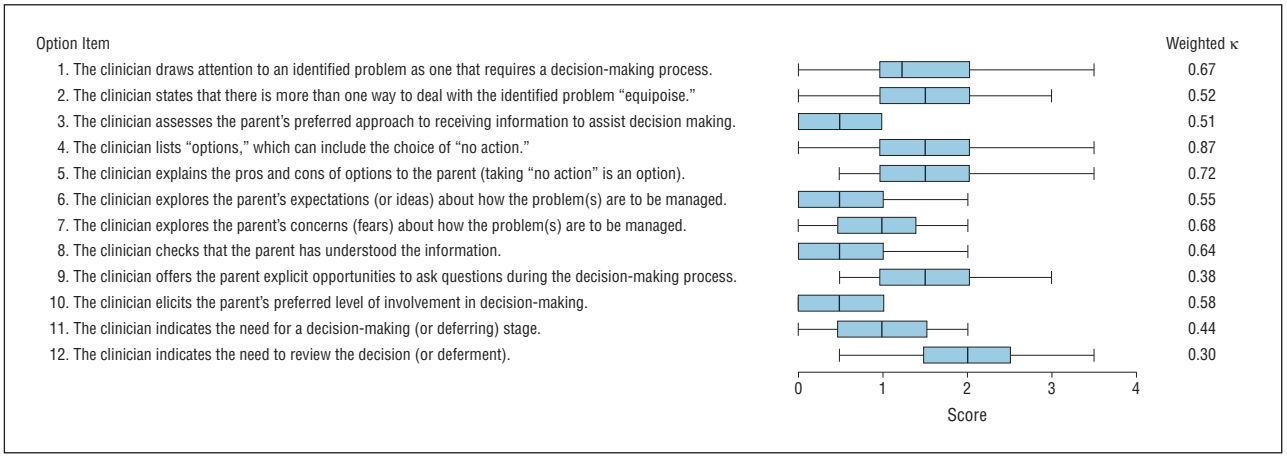

Figure. Box plots of the 12-item Observing Patient Involvement (OPTION) scale. Scores are based on a scale of 0 to 4, with 0 indicating that the behavior was not observed and 4 indicating that the behavior was exhibited to a high standard. The middle line indicates the median; sides of the box, 25th and 75th percentiles; whiskers, minimum and maximum values.

physician made them feel like a partner in care. In contrast, another study[12] found that only 44% of parents of a child with psychosocial problems reported that their child's physician always asked about the parents' ideas and opinions when planning care. Although survey data seem to indicate that many parents of children with ADHD experience a collaborative treatment-planning process, no studies have directly observed the physician-parent treatment-planning interaction, to our knowledge. The objective of this study was to describe physician behavior during treatment-planning encounters for children newly diagnosed as having ADHD. This study addresses the following questions: (1) How much SDM occurs during the initial encounter to develop an ADHD treatment plan? (2) Which of the behaviors that encompass SDM are most common in this context? (3) What characteristics of the physician, child, parent, and visit are associated with higher levels of SDM?

METHODS

STUDY DESIGN, SETTING, AND PARTICIPANTS

We conducted a prospective cohort study in the Cincinnati, Ohio; northern Kentucky; and southeast Indiana regions from October 5, 2009, through August 9, 2010. We recruited 10 general pediatricians from a convenience sample of 7 practices. Physicians provided written informed consent. We attempted to recruit approximately 3 families with ADHD per physician for participation in the study. Eligible families were English speaking and had a child aged 6 to 10 years being assessed for ADHD. Exclusion of older children ensured that parents and physicians were the primary decision-makers.

PROCEDURES

A member of the office staff at each practice served as a research liaison to identify potentially eligible study participants at the time ADHD assessment was initiated. The research liaison requested the parents' permission for research staff to contact them with more information regarding the study. Research staff telephoned these families and subsequently met face to face with those interested in study participation for informed consent and assent. After enrollment in the study, the consenting parent or legal guardian who self-identified as the child's primary caregiver completed surveys of demographic and other baseline characteristics. At the family's physician encounter to discuss treatment-planning, a research assistant set up videorecording equipment, started recording, and left the examination room. The research assistant retrieved the videorecording equipment after the encounter had concluded. Physicians received no reimbursement or incentive to participate. Parents received a $10 gift card as reimbursement for their time. This study was approved by the Institutional Review Board at Cincinnati Children's Hospital Medical Center.

MEASURES OF PARTICIPANT CHARACTERISTICS

Physicians reported on demographic and practice characteristics. Physician assessment practices were documented by auditing the medical record of enrolled patients. Parents or guardians reported on demographic characteristics for their children and themselves. Parent literacy level was estimated using the Rapid Estimate of Adult Literacy in Medicine–Short Form, a validated 7-item scale.[13] Parent numeracy level was estimated using the Subjective Numeracy Scale, a validated 8-item scale.[14,15] Parental report of their own psychological distress was collected using the K6 scale, a validated, 6-item screen for serious mental illness.[16] The scale produces a total score with range from 0 (no distress) to 24 (maximal distress). Scores of 13 or higher are suggestive of serious mental illness.[16]

MEASURE OF SDM

The 12-item Observing Patient Involvement (OPTION) scale was used to code physician behavior when developing a treatment plan (see the **Figure** for item content). OPTION ratings have been shown to be reliable and valid.[17] To be applicable to the pediatric setting, where parents serve as proxy decision-makers, references to "patient" were replaced with "parent." After watching the recording, coders rated each item on a magnitude-based scale from 0 to 4, with 0 indicating that the behavior was not observed and 4 indicating that the behavior was exhibited to a high standard. A total score was calculated by summing the item scores, dividing by 48 (ie, the maximum total score), and multiplying by 100. The resulting total score had a range from 0 (no parental involvement) to 100 (maximal parental involvement). In previous research, OPTION scores have been low during usual care visits in adult health care settings, including primary care,[18-23] psychiatry,[24,25] cardiology,[26] and an-

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esthesiology,[27] with an OPTION score mean (SD) of 23.0 (10.5) across these 10 studies.

Coder training included reviewing OPTION scale coding instructions, coding practice sessions using audiotapes of encounters included with scale instructions, and discussion of practice session codes to establish high coder stability and intercoder reliability. Two research assistants coded every videorecorded encounter independently. To maintain intercoder reliability, independently coded sessions were reviewed and discussed. Interrater reliability on total score was computed using intraclass correlation coefficients (0.81).[28] Interrater reliability on individual items was calculated using weighted κ coefficients (Figure).[29] To maximize the accuracy of our estimates, we calculated a mean score for each OPTION item using the independent ratings obtained from the 2 research assistants. Mean item scores were used to calculate the OPTION total score used in subsequent analyses. Visit duration was calculated from the entrance of the physician into the examination room until he or she exited that room at the end of the visit.

STATISTICAL ANALYSIS

Descriptive statistics were calculated for participant characteristics and OPTION scores. Box plots were used to depict the distributions of scores for the 12 OPTION items. Exploratory analyses examined the relationship between participant characteristics and OPTION scores. Spearman partial rank-order correlations were conducted for continuous and ordinal data. Generalized estimating equations were used for dichotomous variables. These analyses accounted for the clustering of OPTION scores within physicians. The number of physicians (n=10) and families (n=26) precluded us from conducting multivariable analyses.

RESULTS

Physicians were predominantly male and white (**Table 1**). The mean (SD) number of videorecorded encounters per physician was 2.6 (1.0), with a range of 1 to 4. The median visit duration was 37.8 minutes (range, 16.7-134.8 minutes).

Of the 51 families approached by the research team, 33 (65%) agreed to participate. Among the 18 that did not enroll, the most common reasons were that the parent did not return the researcher's call (6/18 [33%]), the parent and/or the child did not want to be videorecorded (4/18 [22%]), and the family was too busy (3/18 [17%]). Videorecorded encounters were not available for 2 enrolled families because of a malfunction of the recording equipment. Four videorecorded encounters were excluded because the physician did not establish a diagnosis of ADHD.

Initial review of the 27 videorecorded encounters involving development of an ADHD treatment plan revealed that none of the 10 physicians framed the decision as an explicit choice of behavioral therapy only, medication only, or a combination of both. One family was interested in behavioral treatment only and asked the physician not to discuss medication options. For the remaining 26 families, treatment decisions focused on initiation of medication treatment. In response to this observation, we coded for the extent that physicians involved parents in selecting a medication, recognizing that stimulant medications can differ regarding attributes that are important to families, such as duration, mode of administration, and out-of-pocket cost. Therefore, the current analysis included 26 families with a videorecorded encounter that involved a decision made regarding initiation of medication treatment.

Table 1. Characteristics of 10 Physicians and 26 Patients

Characteristic	No. (%)[a]
Physician demographics	
Male sex	9 (90)
Hispanic	0
White	9 (90)
African American	1 (10)
Physician age, mean (SD), y	48.7 (9.7)
Years at current practice location, mean (SD)	13.4 (9.1)
No. of patients with ADHD seen per week, mean (SD)	11.0 (9.1)
No. of physicians in practice, mean (SD)	5.7 (3.9)
Patients with public health insurance coverage, mean (SD), %	24.3 (34.6)
Physician assessment practices for children with ADHD enrolled in the study	
Presence of parental ADHD rating scale	24 (92)
Presence of teacher ADHD rating scale	23 (88)
Presence of psychologist assessment report	7 (27)

Abbreviation: ADHD, attention-deficit/hyperactivity disorder.
[a] Data are expressed as number (percentage) of patients or practices unless otherwise indicated.

Most children were boys (62%) and white (81%), with a mean (SD) age of 8.0 (1.2) years (**Table 2**). In all but 1 case, the child's parent or guardian who self-identified as the primary caregiver was one of the biological parents. Most parents completing the survey were women (92%) and married (62%). A second parent or guardian was present for 14 of the 26 visits (54%). Among these 14 visits, 11 parents or guardians were married, 2 were separated, and 1 divorced. For the remaining 12 visits, the only parent or guardian present at the encounter was the child's mother. Most parents or guardians attending the visit had completed at least some college education (61%) (Table 2). Five parents (19%) screened positive for likely serious mental illness.

The extent to which the 12 behaviors that encompass SDM on the OPTION scale were observed is depicted in the Figure. Median item scores were lower for physician assessment of parental preferences, expectations, concerns, and information needs and relatively higher for physician behaviors related to information giving. Total OPTION scores had a mean (SD) of 28.5 (11.7) (range, 10.4-54.2).

Demographic characteristics with little variation (eg, physician sex, physician ethnicity/race, child ethnicity, and parent/guardian sex) or no plausible relation to OPTION score (eg, number of physicians in practice) were excluded from exploratory analyses. Analyses exploring the relationship between visit and physician characteristics and OPTION score were not significant (**Table 3**). The presence of both parents at the encounter was not related to the OPTION score.

Analyses exploring relationships between child characteristics and OPTION score (**Table 4**) found that SDM was higher during encounters involving families with white vs nonwhite children (adjusted mean difference

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Table 2. Characteristics in 26 Families

Characteristic	No. (%)[a]
Child	
Demographics	
Male	16 (62)
White	21 (81)
African American	2 (8)
Other race	3 (12)
Age, mean (SD), y	8.0 (1.2)
Health insurance coverage type	
Private	20 (77)
Public	6 (23)
Parent or Legal Guardian	
Relationship to child	
Parent	25 (96)
Grandparent	1 (4)
Sex	
Male	2 (8)
Female	24 (92)
Age, mean (SD), y	38.8 (9.0)
Marital status	
Single	4 (15)
Married	16 (62)
Separated	2 (8)
Divorced	4 (15)
Female	
Educational level	
Some high school	3 (12)
High school graduate	7 (27)
Some college	3 (12)
2-Year college or technical school	4 (15)
4-Year college graduate	4 (15)
Any postgraduate work	5 (19)
Male[b]	
Educational level	
Some high school	1 (7)
High school graduate	4 (29)
Some college	5 (36)
2-Year college or technical school	1 (7)
Any postgraduate work	2 (14)
Missing	1 (7)
Grade-level medical literacy	
Fourth-sixth	1 (4)
Seventh-eighth	2 (8)
≥Ninth	23 (88)
Subjective numeracy	
High (total score >4.8)	7 (27)
Average (total score 3.2-4.8)	13 (50)
Low (total score <3.2)	6 (23)
Serious mental illness (total score ≥13)	5 (19)

[a] Data are expressed as number (percentage) of children or parents or guardians unless otherwise indicated.
[b] Limited to those who attended the encounter (n=14).

score, 14.9; 95% CI, 10.2-19.6; $P<.001$) and with private vs public health insurance coverage (adjusted mean difference score, 15.1; 95% CI, 11.2-19.0; $P<.001$). Among the parent characteristics (Table 4), parent/guardian age and marital status were not related to the OPTION score. More SDM was observed during encounters with mothers with at least some college education vs those who were a high school graduate or less (adjusted mean difference score, 12.3; 95% CI, 7.2-17.4; $P<.001$). However, neither the educational level of the male parent or guardian present at the visit nor the literacy or numeracy level of the parent or guardian completing the survey was related to the OPTION score. Shared decision-making was significantly higher with parents who did not screen positive for serious mental illness vs those who did (adjusted mean difference score, 15.0; 95% CI, 11.9-18.1; $P<.001$).

Table 3. Relationship Between Physician-Practice Characteristics and OPTION Score

Characteristic	Spearman Rank-Order Correlation Coefficient (95% CI)[a]	*P* Value
Age	−0.50 (−0.86 to 0.19)	.14
Years at current practice location	−0.04 (−0.65 to 0.60)	.91
No. of patients with ADHD seen per week	0.38 (−0.33 to 0.81)	.29
Patients with public health insurance coverage, %	−0.45 (−0.90 to 0.46)	.33
Visit duration, min	0.15 (−0.38 to 0.59)	.58

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; CI, confidence interval; OPTION, Observing Patient Involvement.
[a] Using mean OPTION score by physician (n=10) or practice (n=7).

COMMENT

Treatment decision-making focused on initiation of medication treatment. A low yet variable amount of SDM behavior was directly observed between physicians and parents or guardians in our study. Physicians gave relatively more information regarding medication options than they elicited information regarding parent preferences, expectations, concerns, or information needs. More SDM was observed during encounters involving families with white children, with private health insurance coverage, with higher maternal educational level, and without parental serious mental illness.

It is striking that decision-making was focused on medication treatment initiation despite guidelines suggesting that stimulant medication and/or behavioral therapy be recommended, as appropriate, based on the needs, values, and preferences of the individual family.[7,8] Plausible explanations for this finding exist. By the time parents raise issues related to ADHD treatment with their physician, they may believe they have exhausted behavioral approaches and must resort to trying medication.[30,31] Physicians may believe themselves to be ill-equipped to discuss behavioral therapy because they do not directly provide this treatment[32] or may limit referrals for behavioral therapy due to concerns regarding availability and/or cost.[33-35]

The low level of SDM in our study provides a stark contrast to the findings of previous studies. Using parental reports, Fiks et al[11] estimated that 65% of parents of children with ADHD received a high level of SDM. Also, Toomey et al[10] reported that 85% of parents of children with ADHD reported that they felt like a partner in care "usually" or "always." Using direct observation methods, we found that physicians involved parents to a lesser degree in decision-making when initiating use of medi-

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Table 4. Relationship Between Child and Parent or Legal Guardian Characteristics and OPTION Score

Characteristic	Comparison	Mean Difference (95% CI)[a]	*P* Value[b]
Child sex	Male – female	0 (–10.5 to 10.5)	>.99
Child race	White – nonwhite	14.9 (10.2 to 19.6)	<.001
Child age	Spearman rank-order correlation coefficient	0.4 (–0.1 to 0.8)	.08
Child health insurance coverage type	Private – public	15.1 (11.2 to 19.0)	<.001
Parent or guardian age	Spearman rank-order correlation coefficient	–0.1 (–0.6 to 0.4)	.68
Parent or guardian marital status	Married – not married	2.0 (–6.7 to 10.6)	.65
Female parent or guardian educational level	Some college or more – high school graduate or less	12.3 (7.2 to 17.4)	<.001
Male parent or guardian educational level[c]	Some college or more – high school graduate or less	3.0 (–5.8 to 11.8)	.50
Parent or guardian level of medical literacy	≥Ninth grade – <ninth grade	5.6 (–3.7 to 14.8)	.24
Parent or guardian subjective numeracy	Average to high – low numeracy	2.0 (–3.3 to 7.3)	.45
Parent or guardian psychological distress	Unlikely – likely serious mental illness	15.0 (11.9 to 18.1)	<.001

Abbreviations: CI, confidence interval; OPTION, Observing Patient Involvement.
[a] All mean differences and correlation coefficients are adjusted to account for clustering of OPTION scores within physician.
[b] *P* value for testing difference in means or for testing correlation equal to 0.
[c] Limited to those who attended the encounter.

cation for their child newly diagnosed as having ADHD. A few possible explanations can be found for these discrepancies in findings across studies. First, the methods used in these studies were different. Our study used an objective third-party coding of behaviors directly observed in videorecorded encounters, but the previous studies were based on parent retrospective responses regarding their subjective experiences of care. Although both perspectives are valid and important, research has shown that they can differ.[36] To our knowledge, no pediatric studies have been published that use the OPTION scale with which to compare our findings. However, similarly low OPTION scores have been reported for usual care visits in adult primary care settings for a variety of conditions,[20-23] including depression.[18,19] Second, some behaviors not captured by the OPTION scale may be perceived by parents as being partnership-building. For example, in previous qualitative research by one of us,[30] it was found that physician framing of the initiation of medication as a time-limited trial of treatment helped parents to feel like partners in care. Third, it is possible that our small sample of pediatricians involved parents less in decision-making than the average pediatrician does; this explanation seems unlikely. While masked to the measurement of SDM, the current sample volunteered to be videorecorded discussing ADHD treatment plans with families and likely self-selected based on confidence in their ability to effectively communicate with families and to deliver high-quality ADHD care. Physician barriers to SDM were found in a recent qualitative study of pediatricians who reported attempting to convince parents of children with ADHD to accept the physician's preferred option rather than to elicit the parent's preferences.[35]

Physicians in our study scored relatively higher on OPTION items related to providing information compared with items related to eliciting parent preferences, expectations, concerns, or information needs. Similarly, Cox et al[37] found that physician utterances related to giving information were nearly 2-fold more frequent than those related to gathering information during observed pediatric acute care visits. Barriers may exist to physicians eliciting and/or parents sharing their preferences, expectations, and concerns. Although visit duration was not associated with the extent of parental involvement in decision-making in this study, such relations have been documented in previous research.[19,37-39] Physicians in our study spent a long time with parents (ie, a median of 37 minutes) but were typically trying to discuss the diagnosis and to establish a treatment plan within the same visit. Interventions that establish a foundation of parental understanding regarding ADHD and treatment options before this encounter may relieve the information-provision burden on physicians and may facilitate parental sharing of preferences, expectations, and concerns regarding the ADHD diagnosis and possible treatments. One potential intervention is the use of patient and parental decision aids that facilitate SDM by augmenting physician communication with written and graphic information regarding treatment options and help patients or parents to clarify their personal values. Strong evidence exists that decision aids produce decision makers who are more informed, more involved, and more certain.[40]

More SDM was observed during encounters involving families with white children, private health insurance coverage, and higher maternal educational level. Past studies[39,41] of participatory decision-making among adult medical professionals found similar relationships with patient race and educational level. The results are mixed in large surveys of parents of children with ADHD reporting on the communication skills of their child's physician that characterize SDM. One study[10] found a disparity (based on race and health insurance coverage) but another[11] did not. Larger direct observation studies in multiple environments are needed to confirm our findings.

The number of parents screening positive for likely serious mental illness in our sample is not surprising, given the rates of mental illness documented among parents of children in primary care settings[42] and among parents of children with ADHD.[43] Shared decision-making was lower during encounters involving these parents. It is unknown whether physicians in the current study were aware of this and limited parental involvement because of concerns regarding their decision-making capacity. Although no pediatric studies have examined the extent of

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SDM and parent mental health, to our knowledge, participation in decision-making was found to be unrelated to the severity of depression among adult patients.[44] Additional studies are needed to better understand the usefulness of SDM among patients or parents with mental illness.[45]

Exploratory analyses must be interpreted cautiously, given the relatively small sample size in this labor-intensive, direct observation study. Our study was not specifically powered to detect or to exclude associations between parent, child, physician, and visit characteristics and the extent of SDM. Clustering of a small number of encounters (1-4) within a small number of physicians (n=10) precluded us from conducting multivariable analyses. Some confounding among variables is likely.

This study has additional limitations. First, the small sample of physicians may have introduced bias. All were pediatricians, so our findings may not apply to other health care professionals who care for children with ADHD. Most were men, so we were unable to examine the effect of physician sex on communication. Important differences could be present across sex because previous studies have found that female physicians give less information[37] and use a more participatory style.[39,41] Second, the current study was not designed to determine the extent to which the amount of SDM was a reaction to certain parent characteristics or behaviors vs a physician trait independent of such factors, although extant literature suggests both likely are influential.[19,26] Third, although the participation rate in our study (65%) is comparable to that achieved in other studies involving videorecording of medical encounters,[37,46] parents willing to be videorecorded may differ from those who are not. Finally, the current study was limited to the initial treatment-planning visit. As with any chronic condition, ADHD treatment plans are revisited and revised.[30] Future studies should examine whether the extent of SDM increases in subsequent visits as parents gain experience with different treatment modalities and their child's response to them.

Shared decision-making during the treatment-planning process for children newly diagnosed as having ADHD is limited. Exploratory analyses identified potential disparities and barriers. Given the potential benefits of this approach, interventions to facilitate SDM appear to be warranted for all parents, especially those of nonwhite race, of lower socioeconomic status, of lower educational level, and with serious mental illness.

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