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

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Abstract

Objectives—To describe the amount of shared decision-making (SDM) behavior exhibited during treatment planning encounters for children newly diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD) and to explore relationships between participant characteristics and amount of SDM

Design—Prospective cohort study

Setting—Seven community-based primary care pediatric practices in the Cincinnati/Northern Kentucky/Southeast Indiana Region from October 5, 2009 to August 9, 2010

Participants—Ten pediatricians and 26 families with a 6–10 year old child newly diagnosed with ADHD

Outcome Measure—Amount of SDM behavior exhibited during video-recorded encounters as coded by two independent raters using a validated scale that produces a score ranging from 0 (no parental involvement) to 100 (maximal parental involvement)

Results—Treatment decisions focused on medication initiation. The mean (SD) SDM score was 28.5 (11.7). More SDM was observed during encounters involving families with Caucasian children vs. non-Caucasian (adjusted mean difference score=14.9 [95% confidence interval=10.2, 19.6], p<0.001), private vs. public insurance (adjusted mean difference score=15.1 [11.2, 19.0], p<0.001), mothers with at least some college education vs. high school graduate or less (adjusted mean difference score=12.3 [7.2, 17.4], p<0.001), 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<0.001).

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 minority race, lower economic status, lower education level, and with serious mental illness.

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] SDM involves practitioners communicating information about treatment options and patients/parents communicating the personal value they place on benefits versus harms so that agreement on the best strategy for the individual patient can be reached.[4] Treatment decisions with two or more medically reasonable alternatives are conducive to a SDM process. One such decision, common to pediatric primary care settings[5], is treatment of

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attention-deficit/hyperactivity disorder (ADHD). There is convincing evidence for three treatment strategies (e.g. behavior therapy alone, stimulant medication alone, or both combined). However, the potential benefits (e.g. ADHD symptom reduction) and harms (e.g. side effects, 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 like ADHD. What is known is based on physician- or parent-report. The majority of primary care physicians in one study reported involving parents of children with ADHD in decision-making.[9] Similarly, in two large surveys parents of children with ADHD reported that their child's doctor made them feel like a partner in care.[10,11] In contrast, another study found only 44% of parents of a child with psychosocial problems reported that their child's doctor always asked about his/her ideas and opinions when planning care.[12] While 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. The objective of the current study was to describe physician behavior during treatment planning encounters for children newly diagnosed with 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/Northern Kentucky/Southeast Indiana Region from October 5, 2009 to 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 6–10 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 subjects at the time ADHD assessment was initiated. The research liaison requested parent's permission for research staff to contact them with more information about the study. Research staff phoned 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/guardian who self-identified as the child's primary caregiver, completed surveys with demographic and other baseline characteristics. At the family's physician encounter to discuss treatment planning, a research assistant set up video-recording equipment, started recording, and left the exam room. The research assistant retrieved the video-recording equipment after the encounter concluded. Physicians received no reimbursement/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/

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guardians reported on child and self-demographic characteristics. 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] Parent 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 ≥ 13 are suggestive of serious mental illness.[16]

MEASURE OF SHARED DECISION-MAKING

The 12-item Observing Patient Involvement (OPTION) scale was used to code physician behavior when developing a treatment plan (see Figure for item content). OPTION ratings have been shown to be reliable and valid.[17] In order 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 zero indicating that the behavior was not observed and four indicating that the behavior was exhibited to a high standard. A total score was calculated by summing the mean item scores, dividing by 48 (i.e., 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 anesthesiology[27] with an OPTION score mean (standard deviation [SD])=23.0 (10.5) out of 100 across these 10 studies.

Coder training included 1) reviewing OPTION scale coding instructions, 2) coding practice sessions using audiotapes of encounters included with scale instructions, and 3) discussion of practice session codes to establish high coder stability and inter-coder reliability. Two research assistants coded every video-recorded encounter independently. To maintain inter-coder reliability, independently coded sessions were reviewed and discussed. Inter-rater reliability on total score was computed using intra-class correlation coefficients (ICC = 0.81).[28] Inter-rater reliability on individual items was calculated using weighted kappa coefficients (see 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 two research assistants. Mean item scores were used to calculate the OPTION total score used in subsequent analyses.

Visit duration was calculated from entrance of the physician into the exam room until the physician exited the exam room at the end of the visit.

ANALYSIS

Descriptive statistics were calculated for participant characteristics and OPTION scores. Box plots were used to depict the distributions of scores on 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 physician. The number of physicians (n=10) and families (n=26) precluded us from conducting multivariable analyses.

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RESULTS

Physicians were predominantly male and Caucasian (Table 1). The mean (SD) number of video-recorded encounters per physician was 2.6 (0.97), with a range of 1 to 4. Median visit duration was 37.8 minutes (range of 16.7 to 134.8).

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

Initial review of the 27 video-recorded encounters involving development of an ADHD treatment plan revealed that none of the 10 physicians framed the decision as an explicit choice between behavior therapy alone, medication alone, or both combined. One family was only interested in behavioral treatment and asked the physician not to discuss medication options. For the remaining 26 families, treatment decisions focused on initiation of medication. In response to this observation, we coded for the extent that physicians involved parents in selecting a medication, recognizing that stimulant medications can differ on 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 video-recorded encounter that involved a decision made about medication initiation.

A majority of children were male (61.5%) and Caucasian (80.8%) with a mean (SD) age of 8 (1.2) years (Table 2). In all but one case, the child's parent/guardian who self-identified as the child's primary caregiver was one of the child's biological parents. A majority of the parents completing the survey were female (92.3%) and married (61.5%). A second parent/guardian was present for 53.9% (14/26) of visits. Among these 14 visits, 11 parents/guardians were married, two were separated, and one divorced. For the remaining 12 visits, the only parent/guardian present at the encounter was the child's mother. The majority of parents/guardians attending the visit had completed at least some college education (61.5%) (Table 2). Five parents (19.2%) 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 parent 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) out of 100, range 10.4 to 54.2.

Variables with little variation (e.g. physician gender, physician ethnicity/race; child ethnicity; parent gender, etc.) or no plausible relation to OPTION score (e.g. 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). Presence of both parents at the encounter was not related to OPTION score.

Analyses exploring relationships between child characteristics and OPTION score (Table 4) found that SDM was higher during encounters involving families with Caucasian children vs. non-Caucasian (adjusted mean difference score=14.9 [95% confidence interval=10.2, 19.6], $p<0.001$) and private vs. public insurance (adjusted mean difference score=15.1 [11.2, 19.0], $p<0.001$), Among parent characteristics (Table 4), parent age and marital status were not related to OPTION score. More SDM was observed during encounters with mothers with at least some college education vs. high school graduate or less (adjusted mean

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difference score=12.3 [7.2, 17.4], p<0.001). However, neither the education level of the male parent/guardian present at the visit nor the literacy or numeracy level of the parent/guardian completing the survey was related to OPTION score. SDM was significantly higher with 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<0.001).

Discussion

Treatment decision-making focused on initiation of medication. A low yet variable amount of SDM behavior was directly-observed between physicians and parents/guardians in our study. Physicians engaged in relatively more information-giving about medication options than they elicited information about parent preferences, expectations, concerns, or information needs. More SDM was observed during encounters involving families with Caucasian children, private insurance, higher mother education, and without parent serious mental illness.

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

The low-level of SDM in our study provides a stark contrast to previous studies. Using parent-report, Fiks et al.[11] estimated 65% of parents of children with ADHD received a ‘high-level’ of SDM. Also, Toomey et al.[10] reported 85% of parents of children with ADHD self-reported that they felt like a partner in care ‘usually’ or ‘always.’ Using direct-observation methods, we found that physicians involved parents to a low-level in decision-making when initiating medication for their child newly diagnosed with ADHD. There are a few possible explanations for these discrepancies in findings across studies. First, the methods employed in these studies were quite different. The current study used an objective third-party coding of behaviors directly-observed in video-recorded encounters whereas the previous studies were based on parent retrospective responses about their subjective experiences of care. While both perspectives are valid and important, research has shown that these viewpoints can differ.[36] There are no pediatric studies employing 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, there may be some behaviors that parents perceive as partnership-building that are not captured by the OPTION scale. For example, in our previous qualitative research we found that physician framing the initiation of medication as a time-limited ‘trial of treatment’ helped parents to feel like partners in care.[30] Third, it is possible that our small sample of pediatricians involved parents less in decision-making than the ‘average’ pediatrician. This explanation seems unlikely. While blinded to the measurement of SDM, the current sample volunteered to be video-recorded discussing ADHD treatment plans with families and likely self-selected based on confidence in their ability to effectively communicate with families and 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 clinician’s preferred option rather than elicit the parent’s preferences.[35]

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Physicians in the current study scored relatively higher on OPTION items related to providing information compared to 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 two-fold more frequent than those related to information gathering during observed pediatric acute care visits. There may be barriers to physicians eliciting and/or parents sharing their preferences, expectations, and concerns. While visit duration was not associated with the extent of parent involvement in decision-making in this study, such relations have been documented in previous research.[19,37–39] Physicians in the current study spent a large amount of time with parents (i.e. median of 37 minutes), but were typically trying to discuss the diagnosis and establish a treatment plan within the same visit. Interventions that establish a foundation of parent understanding about ADHD *and* treatment options prior to this encounter may relieve the information provision burden of physicians and facilitate parent sharing of preferences, expectations, and concerns about the ADHD diagnosis and possible treatments. One potential intervention is the use of patient/parent decision aids which facilitate SDM by augmenting physician communication with written and graphical information on treatment options and help patients/parents to clarify their personal values. There is strong evidence that decision aids produce decision-makers that are more informed, more involved, and more certain.[40]

More SDM was observed during encounters involving families with Caucasian children, private insurance, and higher mother education. Past studies of participatory decision-making among adult medical providers found similar relationships with patient race and education.[39,41] The results are mixed in large surveys of parents of children with ADHD reporting on the communication skills of their child's doctor that characterize SDM. One study found a disparity (based on race and insurance coverage)[10] while another study did not.[11] 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] SDM was lower during encounters involving these parents. It is unknown whether physicians in the current study were aware of this and limited parent involvement due to concerns about their decision-making capacity. While no pediatric studies have examined extent of SDM and parent mental health, 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 utility of shared decision-making among patients/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 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. There is likely some confounding among variables.

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 professionals who care for children with ADHD. Most were male, so we were unable to examine the effect of physician gender on communication. There may be important differences across gender, as previous studies have found female physicians give less information[37] and use a more participatory style.[39,41] Second, the current study was not designed to determine the

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extent to which amount of SDM was a reaction to certain parent characteristics or behaviors versus a physician trait independent of such factors, though extant literature suggests both are likely influential.[19,26] Third, while the participation rate in our study (65%) is comparable to that achieved in other studies involving video-recording of medical encounters,[37,46] parents willing to be video-recorded 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.

Conclusion

SDM during the treatment planning process for children newly diagnosed with ADHD is limited. Exploratory analyses identified potential disparities and barriers. Given the potential benefits of this approach, interventions to facilitate SDM appear warranted for all parents, especially those of minority race, lower economic status, lower education level, and with serious mental illness.

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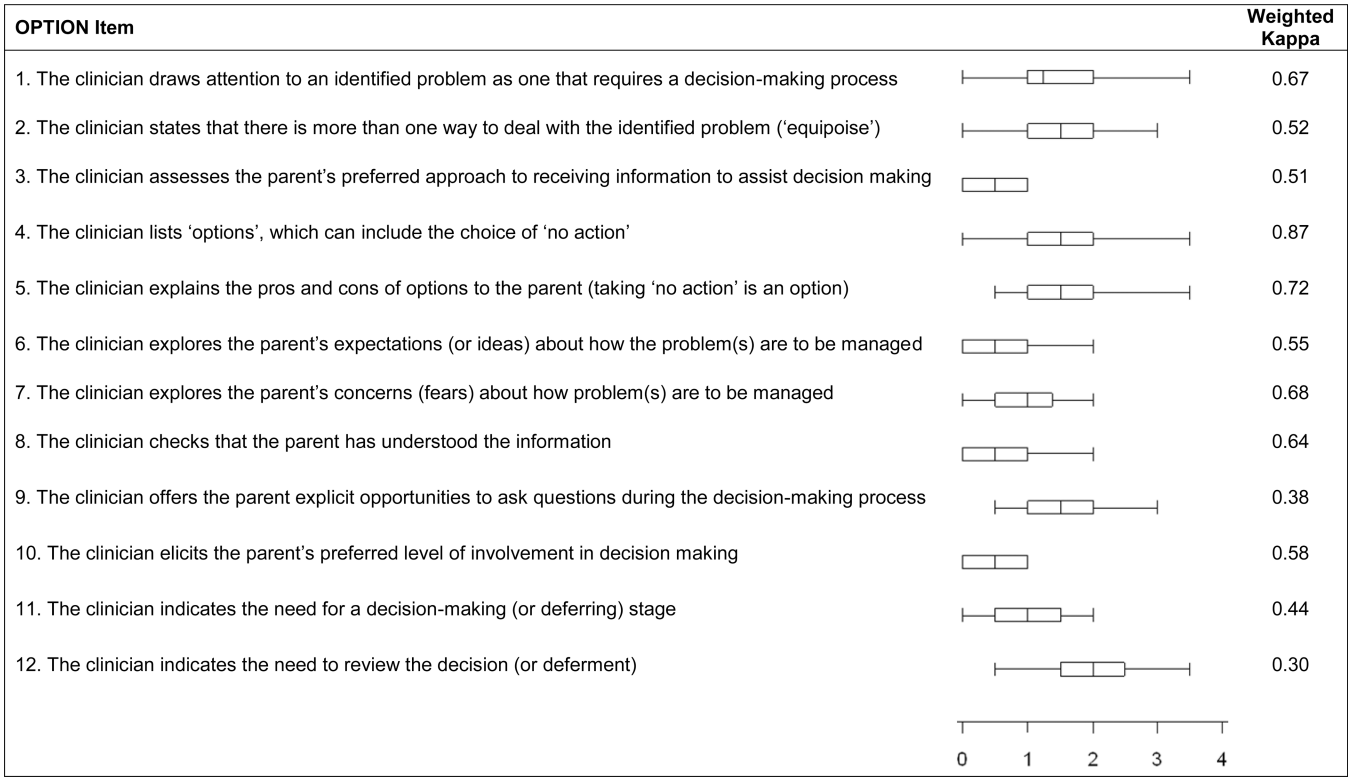

Figure. Boxplots of OPTION scale items and item-level reliability

middle line in box=median, sides of box=25th and 75th percentiles, whiskers=min and max values; scale from 0–4, with zero indicating that behavior was not observed and four indicating that behavior was exhibited to a high standard.

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Table 1

Physician/Practice Characteristics

		No. (%)
Gender	Male	9 (90)
Ethnicity	Hispanic	0
Race	Caucasian	9 (90)
	African-American	1 (10)
		Mean (SD)
Age	Years	48.7 (9.7)
Years at practice	Years	13.4 (9.1)
Number of ADHD patients seen per week		11.0 (9.1)
Number of physicians in practice		5.7 (3.9)
Percentage of patients with public insurance		24.3 (34.6)
		No (%)
Physician assessment practices for ADHD children enrolled in study	Presence of parent ADHD rating scale	24 (92.3)
	Presence of teacher ADHD rating scale	23 (88.5)
	Presence of psychologist assessment report	7 (26.9)

No. = number, % = percentage, SD = standard deviation

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Table 2

Child/Parent Characteristics

		No. (%)
Child gender	Male	16 (61.5)
Child ethnicity	Hispanic	0
Child race	Caucasian	21 (80.8)
	African-American	2 (7.7)
	Other	3 (11.5)
Child age	Years, mean (SD)	8.0 (1.2)
Child insurance	Private insurance	20 (76.9)
	Public insurance	6 (23.1)
Parent/guardian relationship to child	Parent	25 (96.1)
	Grandparent	1 (3.9)
Parent/guardian gender	Male	2 (7.7)
	Female	24 (92.3)
Parent/guardian age	Years, mean (SD)	38.8 (9.0)
Parent/guardian marital status	Single	4 (15.4)
	Married	16 (61.5)
	Separated	2 (7.7)
	Divorced	4 (15.4)
Female parent/guardian education	Some High School	3 (11.5)
	High School Graduate	7 (26.9)
	Some College	3 (11.5)
	2 yr college/tech. school	4 (15.4)
	4 yr college graduate	4 (15.4)
	Any post-graduate work	5 (19.2)
Male parent/guardian education[a]	Some High School	1 (7.1)
	High School Graduate	4 (28.6)
	Some College	5 (35.7)
	2 yr college/tech. school	1 (7.1)
	Any post-graduate work	2 (14.3)
	Missing	1 (7.1)
Parent/guardian literacy in medicine	4^{th}–6^{th} grade	1 (3.9)
	7^{th}–8^{th} grade	2 (7.7)
	≥ 9^{th} grade	23 (88.5)
Parent/guardian subjective numeracy	High numeracy (total score ≥ 4.8)	7 (26.9)
	Average numeracy (total score 3.2–4.8)	13 (50.0)
	Low numeracy (total score ≤3.2)	6 (23.1)
Caregiver psychological distress	Serious mental illness (total score ≥ 13)	5 (19.2)

No. = number, % = percentage, SD = standard deviation

[a] Limited to those who attended the encounter

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Table 3

Relationship Between Physician-Practice Characteristics and OPTION Score

Characteristic	Spearman correlation coefficient[a]	95% CI	P
Age	−0.50	(−0.86, 0.19)	0.14
Years at practice	−0.04	(−0.65, 0.60)	0.91
Number of ADHD patients seen per week	0.38	(−0.33, 0.81)	0.29
Percentage of patients with public insurance	−0.45	(−0.90, 0.46)	0.33
Visit duration	0.15	(−0.38, 0.59)	0.58

CI = Confidence interval;

[a]Using mean OPTION Score by physician (n=10) or by practice (n=7).

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Table 4

Relationship Between Child/Parent Characteristics and OPTION Score

Characteristic	Comparison	Mean Difference[a]	95% CI	p[b]
Child gender	Male minus female	0.0	(−10.5, 10.5)	1.00
Child race	Caucasian minus non-Caucasian	14.9	(10.2, 19.6)	<0.001
Child age	Spearman correlation coefficient	0.44	(−0.06, 0.76)	0.08
Child insurance	Private minus public insurance	15.1	(11.2, 19.0)	<0.001
Parent/guardian age	Spearman correlation coefficient	−0.11	(−0.56, 0.39)	0.68
Parent/guardian marital status	Married minus not married	2.0	(−6.7, 10.6)	0.65
Female parent/guardian education	At least some college minus high school graduate or less	12.3	(7.2, 17.4)	<0.001
Male parent/guardian education[c]	At least some college minus high school graduate or less	3.0	(−5.8, 11.8)	0.50
Parent/guardian literacy in medicine	≥9th grade minus < 9th grade	5.6	(−3.7, 14.8)	0.24
Parent/guardian subjective numeracy	Average to high minus low numeracy	2.0	(−3.3, 7.3)	0.45
Parent/guardian psychological distress	Unlikely minus likely serious mental illness	15.0	(11.9, 18.1)	<0.001

CI = Confidence interval;

[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 zero;

[c] Limited to those who attended the encounter