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Shared decision-making to improve attention-deficit hyperactivity disorder care

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Abstract

Objective—To examine the effect of a shared decision-making intervention with parents of children newly diagnosed with attention-deficit/hyperactivity disorder.

Methods—Seven pediatricians participated in a pre/post open trial of decision aids for use before and during the office visit to discuss diagnosis and develop a treatment plan. Encounters pre- (n = 21, control group) and post-intervention implementation (n = 33, intervention group) were compared. We video-recorded encounters and surveyed parents.

Results—Compared to controls, intervention group parents were more involved in shared decision-making (31.2 vs. 43.8 on OPTION score, $p < 0.01$), more knowledgeable (6.4 vs. 8.1 questions correct, $p < 0.01$), and less conflicted about treatment options (16.2 vs. 10.7 on decisional conflict total score, $p = 0.06$). Visit duration was unchanged (41.0 vs. 41.6 min, $p = 0.75$). There were no significant differences in the median number of follow-up visits (0 vs. 1 visits, $p = 0.08$), or the proportion of children with medication titration (62% vs. 76%, $p = 0.28$), or parent-completed behavior rating scale to assess treatment response (24% vs. 39%, $p = 0.36$).

Conclusions—Our intervention increased shared decision-making with parents. Parents were better informed about treatment options without increasing visit duration.

Practice implications—Interventions are available to prepare parents for visits and enable physicians to elicit parent preferences and involvement in decision-making.

Keywords

Attention-deficit hyperactivity disorder; Shared decision-making; Decision aids; Family/self-management; Adherence

1. Introduction

The Institute of Medicine and the American Academy of Pediatrics recognize shared decision-making (SDM) as an approach to improve health care quality [1–3]. SDM is a process that involves clinicians communicating information about treatment options and

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Conflict of interest

The authors of this article disclose no financial conflicts of interest pertinent to this study. In particular, the intervention materials described in this article are available in the public domain free of charge at: http://www.cincinnatichildrens.org/shareddecisions.

patients/parents communicating the personal value they place on the trade-offs involved so that agreement on the best strategy for the individual patient can be reached [4]. Treatment decisions with more than one medically reasonable alternative are most conducive to SDM.

To date, few interventions to improve SDM have been tested in pediatrics [5–10]. A commonly treated condition in pediatric primary care settings is attention-deficit hyperactivity disorder (ADHD) [11]. ADHD treatment guidelines recognize the importance of developing a treatment plan that takes into account family goals, preferences, cultural values, and concerns [12,13]. Our previous research documented that at the time treatment is initiated for children newly diagnosed with ADHD, parents and physicians focus their discussion on medication [14]. Despite the fact that ADHD medications can differ on attributes that are important to families such as duration, mode of administration, and out-of-pocket cost, parents had relatively little involvement in selecting a medication [14]. The objective of the current study was to test a SDM intervention designed to increase parental involvement in SDM and knowledge of ADHD treatment options when developing treatment plans for children newly diagnosed with ADHD.

2. Methods

2.1. Study design, setting, and participants

Seven general pediatricians from a convenience sample of 5 practices participated in a pre/post open trial in the Greater Cincinnati Region from October 5, 2009 to January 25, 2012. Physicians provided written informed consent. We attempted to recruit approximately 3 families per physician for participation in the study pre- (control group) and post-intervention implementation (intervention group). Eligible families were English-speaking and had a child aged 6–10 years being assessed for ADHD. Inclusion of younger children, rather than adolescents, ensured that parents and physicians were the primary decision-makers. In this open trial design, the experimental unit is the physician and the observational unit is the parent/child encounter.

2.2. Shared decision-making intervention

The SDM intervention was developed based on criteria established by the International Patient Decision Aids Standards collaboration [15] and informed by qualitative study of the decision making needs of parents of children with ADHD [16]. Intervention materials are written at or below 8th grade reading level [17] and include the following components.

Pre-encounter cards and booklet on ADHD treatment modalities: the cards provide a brief overview of the treatment modalities (i.e. watchful waiting, behavioral treatment, medication treatment, and combination of behavioral and medication treatments) including a description of the process to implement each treatment and the pros and cons of each option. Two cards elicit information from parents to be shared with their child’s doctor at the visit. One card asks parents to write their treatment goals and preferences. Another card asks parents to document the behavioral treatments that parents have tried in the past, are currently trying, or are interested in trying next. The booklet provides greater depth on ADHD treatment modalities and includes background information on ADHD. Parents received the pre-encounter cards and booklet approximately one week before their scheduled visit. Prior to use in this study, these materials had been refined using an iterative process based on feedback from a variety of stakeholders: parents of children with ADHD ($n = 15$), primary care pediatricians who care for children with ADHD ($n = 5$), ADHD experts ($n = 3$), decision aid experts ($n = 2$), a quality improvement expert ($n = 1$), and graphic designers ($n = 7$).

ADHD medication choice cards: we adapted an established issue card format [18,19] that facilitates SDM. The issue cards convey the attributes of ADHD medications that are important to consider, namely “Improvement,” “Side Effects,” “Duration,” “Daily Routine,” and “Cost” (Fig. 1). The issue cards are designed to enable physicians and parents to efficiently discuss medication from the following classes: methylphenidate, amphetamine salts, atomoxetine, and guanfacine. Ideally, the physician presents all 5 issue cards to the parent and asks which of the cards the parent would like to discuss first. After reviewing and discussing the cards that the parent and physician choose to discuss (they do not need to discuss all 5 cards), they arrive at the medication that best matches the family’s circumstances and preferences [19].

Physician training consisted of one 30-min session where intervention materials were reviewed and use of the ADHD medication choice cards was demonstrated. Parents were given the opportunity prior to visits to add personal information to the issue cards regarding their child’s daily routine and estimates of out-of-pocket costs for medications that parents obtained from their child’s healthcare plan. Prior to entering the examination room for each study encounter, physicians were handed the parent-completed goal/preference card, behavioral treatment card, and the ADHD medication choice cards. Physicians were reminded to ask parents to pick a medication choice card to discuss first, if appropriate.

2.3. 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 the 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. The treatment planning clinical encounter was video-recorded. Three months after this encounter the child’s medical record was audited. Physicians were surveyed about their satisfaction using the decision aids at the end of the study. Physicians received no reimbursement/incentive to participate. Parents received $20 in gift cards as reimbursement for their time. This study was approved by the Institutional Review Board at Cincinnati Children’s Hospital Medical Center.

2.4. Measures of participant characteristics

Physicians reported on demographic and practice characteristics. The parent/guardian who self-identified as the child’s primary caregiver 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, with scores reported in four reading level categories (i.e. third grade or below, fourth to sixth grades, seventh to eighth grades, ninth grade or higher) [20]. Parent numeracy level was estimated using the subjective numeracy scale, a validated 8-item scale, with scores reported as low (<25th percentile), average (25th to 75th percentile), or high (>75th percentile) [21,22]. Parent report of their own psychological distress was collected using the K6 scale, a validated, 6-item screen for serious mental illness, with scores of 13 or higher suggestive of serious mental illness on a scale ranging from 0 (no distress) to 24 (maximal distress) [23].

2.5. Primary outcome measures

Shared decision making was measured using the 12-item observing patient involvement (OPTION) scale, which allows an observer to quantify clinician behavior. This scale was developed following a systematic review showing that no ‘observer’ instrument had yet been designed to assess the specific construct of ‘patient involvement’ [24]. Key patient involving behaviors include identifying the problem that requires decision making, explaining equipoise, assessing preferred approach to receiving information, listing options, explaining pros and cons, exploring expectations, exploring concerns, checking understanding, offering opportunities for questions, eliciting preferred involvement, indicating need for decision, and indicating need to review or defer decision. OPTION ratings have been shown to be reliable and valid [25] and previously adapted for use in pediatric settings [14]. After watching the video recording, the 12 items were rated on a Likert scale which ranged 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 has a range from 0 (no SDM) to 100 (maximal SDM). Parent knowledge of ADHD treatment options was measured using a questionnaire, with 13 items with response options ‘true’, ‘false’, and ‘don’t know’ and 2 items with multiple-choice options. Of the 15 items, 11 items were specific to the content of the intervention materials and 4 items were not addressed by the intervention. The number of items answered correctly within each subset, intervention specific and not in intervention, was calculated. This questionnaire was developed by the authors for the current study. It was modeled after knowledge measures used in previous decision aid studies [19,26] and reviewed by ADHD experts for content validity. Parent decisional conflict was measured using the validated 16-item decisional conflict scale [27]. Using response options of strongly agree, agree, neither agree or disagree, disagree, and strongly disagree, parents reported the uncertainty experienced when feeling uninformed about the alternatives, benefits and risks, unclear about personal values, or unsupported in making a choice. The total score has a range from 0 (no conflict) to 100 (maximal conflict). 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.

2.6. Secondary outcome measures

Chart audit was used to examine ADHD care received over the 3 months following the index visit, including follow-up calls and visits, prescriptions written, and parent and teacher ADHD behavioral ratings scales collected. Titration of medication was defined by a child having been prescribed more than one dosage or medication over the 3 months following the index visit. Number of days covered with medicine in the 90 days following the index visit was calculated based on the dates prescriptions were written and the number of pills to be dispensed with each prescription. Physician satisfaction using the ADHD medication choice cards was measured with a questionnaire adapted from previous decision aid studies [19,26].

2.7. Analysis

Descriptive statistics were calculated for physician/practice characteristics and child, parent/guardian characteristics. Differences between control and intervention groups for parent/child characteristics were examined using chi square test, Fisher’s exact, or two sample *t*-test, as appropriate. Generalized linear models with generalized estimating equations to account for within-physician correlation were used to compare control and intervention groups on binary and continuous outcomes using the logistic link and identity link, respectively. The working within-physician correlation was assumed to be identical for each pair of observations, although alternative error structures were entertained.

3. Results

Physicians were male and predominantly Caucasian (Table 1). The mean (SD) number of encounters per physician was 3.0 (0.82) pre- and 4.7 (1.98) post-intervention implementation. A video-recorded encounter was not available for one enrolled family due to recording equipment malfunction.

Recruitment rates were similar pre- and post-intervention implementation. Overall, 63.5% (54/85) of eligible families approached by the research team agreed to participate. Among the 31 that did not enroll, the most common reasons were: parent did not return the researcher's call before their scheduled doctor's visit 41.9% (13/31), family was too busy 22.6% (7/31), parent and/or child did not want to be video-recorded 19.4% (6/31), research staff was not available to enroll family 6.5% (2/31). Twenty-one encounters occurred pre- (control group) and 33 occurred post-intervention implementation (intervention group) on the physician level (Table 2). Nearly two-thirds of children were male and Caucasian. The vast majority of the parents who completed the survey as the child's primary caregiver were mothers, a majority of whom had completed at least some college education. Very few parents/guardians had low health literacy, low numeracy, or screened positive for likely serious mental illness. Child and parent characteristics did not differ significantly between the groups with the exception of marital status, with a higher proportion of married individuals in the intervention group. Of note, over half of the visits were attended by more than one parent/guardian (control: 12/21 = 57.1% vs. intervention: 17/33 = 51.5%, $p = 0.78$), with a similar proportion of these visits attended by two parents who were currently married (control: 10/12 = 83.3% vs. intervention: 15/17= 88.2%, $p = 1.0$).

After implementing the intervention, parents completed the treatment goals and preferences card prior to 90.9% (30/33) of visits and the behavioral treatments card prior to 63.6% (21/33) of visits. Parents added personal information to the ADHD Medication Choice cards regarding their child's daily routine prior to 63.6% (21/33) of visits and out-of-pocket costs for medications prior to 18.2% (6/33) of visits. Physicians had the ADHD medication choice cards available for use during all 33 visits.

Parent involvement in SDM, as measured by the OPTION scale, was significantly higher in the intervention group (Table 3) compared to the control group (interobserver agreement for the OPTION scale score was 0.82). Parents in the intervention group were more knowledgeable and tended to be less conflicted about ADHD treatment options compared to the control group. Visit duration was similar for both groups. There were no significant differences between groups in the number of follow-up calls, visits, the proportion of children with medication titration, the proportion of children with a parent-completed ADHD rating scale to assess response to treatment, or the proportion of days covered with medication during the first 3 months of treatment (Table 4). Physicians reported that the information on cards was acceptable for use with families (Table 5). Of the 7 physicians, 5 (71%) found the information extremely helpful, 6 (86%) recommended use of the cards to other providers, and 3 (43%) expressed interest in having cards for treatment decisions for other conditions.

4. Discussion and conclusion

4.1. Discussion

Parents who received our intervention were more involved in SDM, more knowledgeable, and tended to be less conflicted about treatment options. These benefits accrued with minimal physician training and without significantly increasing visit duration. Physicians were highly satisfied with the intervention. Children in the intervention group received more ADHD follow-up care, but these differences were not statistically significant. Both groups had a similar number of days covered with medication over the 3 months after initial treatment planning visit.

To our knowledge, this is the first study to increase parent involvement in SDM about treatment of their child using a decision aid intervention. While this finding is consistent with four recent studies that used decision aids to increase SDM with adult patients [19,26,28,29], few decision aid interventions have been tested in pediatrics [5–10] and none have measured clinician behaviors to involve parents in the decision-making process. Before implementing our intervention, parent involvement in SDM about treatment options was relatively low, with an average SDM score of 31 points out of 100. Similar levels of SDM, as measured by the OPTION scale, have been reported across a variety of conditions [19,30–32] including depression [33,34] in adult primary care settings. Significant barriers exist to implementing SDM, with visit time constraints being identified most often [35]. It is noteworthy that visit duration was comparable to past reports about ADHD care [36] and not significantly increased by our SDM intervention. Past studies examining this outcome have reported mixed findings with decision aids increasing [37,38], decreasing [39], or not significantly affecting visit duration [40–44]. In aggregate, the evidence suggests that decision aids can be thoughtfully designed to facilitate timely SDM during clinical encounters.

A Cochrane systematic review [45] found decision aids consistently increase patient knowledge and decrease decisional conflict compared to ‘usual care.’ However, few studies involve treatment plans for chronic medical conditions where follow-up care and medication adherence are important. SDM interventions increased medication adherence in two recent studies [26,40] and had no effect in three others [19,46,47].

The process of optimizing ADHD medication treatment is challenging and requires ongoing productive interactions between an informed and activated family and a prepared and proactive practice team [12]. There is much room for improvement in follow-up care, as a majority of children with ADHD have fewer than two visits and/or less than 70% of days covered with ADHD medication in first 10 months of treatment [48]. We explored whether our intervention could drive improvement in measures of follow-up care over the 3 months after it was delivered. ADHD follow-up care increased on all measures after the intervention was implemented, but these differences were not statistically significant. This may reflect an insufficient sample size to detect a small difference or an insufficient intervention to produce a large difference. While intervention materials prepared parents for the process to optimize medication (e.g. trying a range of dosages, monitoring response, communicating with clinician by calls/visits), there were no intervention components to prompt necessary actions after the initial visit. The ADHD Medication Choice cards were designed to optimize the fit between well-informed family preferences and the initial medication selected. While this may provide a good starting point, it does not appear to impact the continuity of medication in the first 3 months of treatment as both groups had, on average, at least 77% (70/90) of days covered with medication. Additional interventions may be needed to promote partnering relationships between families and practice teams to effectively manage medication over time. Systematic approaches are also needed to engage children and adolescents in the management of treatment for ADHD in a developmentally appropriate manner. The need for such interventions is great as many adolescents describe their level of involvement in decisions about their own ADHD care as inadequate [49].

Out-of-pocket medication costs are likely to influence medication choices for many families given the current economic climate and the trend toward high deductible insurance plans. However, only 18% of parents in the intervention group obtained medication cost information prior to their child’s visit. There are three likely explanations for this: (1) cost was important to the parent but no attempt was made to obtain the information, (2) cost was important to the parent but barriers were encountered when attempting to obtain this information, and (3) cost was not important to the parent. Additional study is needed as consideration of personally relevant cost information at the time treatment plans are made may remove a barrier to timely treatment implementation for some families [50].

This study has limitations. First, we opted to employ a pre/post open trial design for this labor-intensive direct-observation study. This design limits our ability to know if unmeasured confounding variables influenced our estimates of intervention effect. Second, 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. All were male. This may have lowered our estimate of the baseline amount of SDM as previous studies have found female physicians use a more participatory style [51,52]. We suspect that any moderating effects of gender were minimal, because our baseline estimates were comparable to the amount of SDM observed in adult primary care settings with female physicians represented [19,30–34]. Our physician sample agreed to be video-recorded discussing ADHD treatment plans with families. While blinded to the measurement of SDM, this group likely self-selected based on confidence in their ability to effectively communicate with families and deliver high-quality ADHD care. Given that provider motivation is the most commonly reported facilitator of SDM [35], our findings should be replicated among a more diverse sample of physicians. Our small convenience sample of parents also may have introduced bias as the intervention group had a significantly higher proportion of married parents than did the control group. One could hypothesize that it might be more challenging for physicians to engage divorced parents in shared decision-making due to conflict arising between parents during the encounter. However, it appears unlikely that this significantly affected our results as a similar proportion of visits in both groups were attended by more than one parent/guardian with a similar proportion of these visits attended by two parents who were currently married. Likewise, the intervention should be tested among parents with lower levels of educational achievement, literacy, and numeracy as these characteristics were underrepresented in the current sample. In addition, the intervention should be tested in minority and lower income populations as past studies have documented differences in ADHD treatment preferences in these groups [53,54]. Finally, while the participation rate in our study (63.5%) is comparable to that achieved in other studies involving video-recording of medical encounters [55,56], parents willing to be video-recorded may differ from those who are not.

4.2. Conclusion

Our intervention increased physician SDM with parents who were better informed about treatment options without increasing visit duration. This may help establish a foundation to support ongoing productive interactions between parents and physicians managing treatment for ADHD.

4.3. Practice implications

Interventions are available to prepare parents for visits and enable physicians to elicit parent preferences and involvement in decision-making.

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Abbreviations

ADHD	attention-deficit hyperactivity disorder
SDM	shared decision-making

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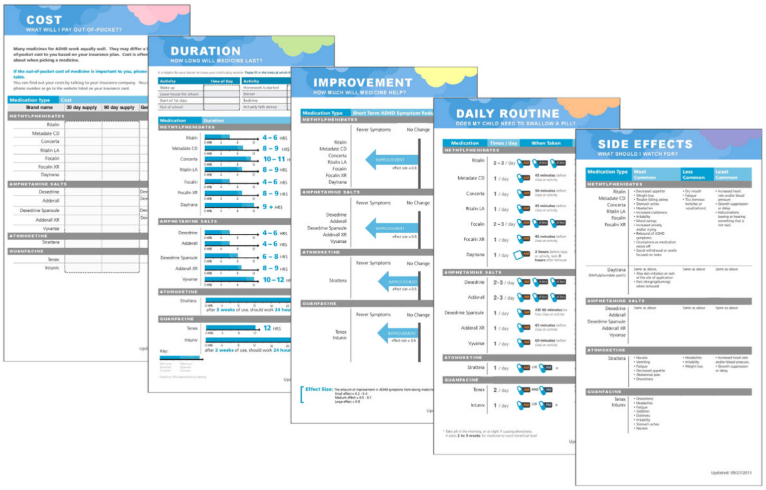

COST
WHAT WILL I PAY OUT-OF-POCKET?

DURATION
HOW LONG WILL MEDICINE LAST?

IMPROVEMENT
HOW MUCH WILL MEDICINE HELP?

DAILY ROUTINE
DOES MY CHILD NEED TO SWALLOW A PILL?

SIDE EFFECTS
WHAT SHOULD I WATCH FOR?

Fig. 1.

The ADHD medication choice cards.

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Table 1

Characteristics of physicians (*n* = 7) and practices (*n* = 5).

		No. (%)
Physician characteristics		
Gender	Male	7 (100)
Ethnicity	Hispanic	0
Race	Caucasian	6 (86)
	African-American	1 (14)
		Mean (SD)
Age	Years	48.7 (8.4)
Years at practice	Years	13.8 (9.7)
Number of ADHD patients seen per week		9.6 (7.3)
Practice characteristics		
Number of physicians in practice		6.4 (4.6)
Percentage of patients with public insurance		12.0 (10.4)

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

Table 2

Child/parent characteristics.

		Control group (n = 21) **No. (%)**	**Intervention group (n = 33)** **No. (%)**	***p***
Child gender	Male	13 (62%)	21 (64%)	1.00
Child ethnicity	Hispanic	0	0	–
Child race	Caucasian	17 (81%)	30 (91%)	0.58
	African-American	2 (10%)	2 (6%)	
	Other	2 (10%)	1 (3%)	
Child age	Years, mean (SD)	7.9 (1.2)	8.4 (1.1)	0.10
Child insurance	Private insurance	18 (86%)	29 (88%)	0.80
	Public insurance	3 (14%)	3 (9%)	
	Both	0	1 (3%)	
Parent/guardian relationship to child	Parent	20 (95%)	32 (97%)	1.00
Parent/guardian gender	Female	19 (90%)	32 (97%)	0.55
Parent/guardian age	Years, mean (SD)	41.7 (8.3)	39.1 (5.7)	0.17
Parent/guardian marital status	Single	2 (10%)	0	0.049
	Married	14 (67%)	30 (91%)	
	Separated	1 (5%)	0	
	Divorced	4 (19%)	3(9%)	
Parent/guardian education	Some high school	0	0	0.20
	High school graduate	5 (24%)	2 (6%)	
	Some college	3 (14%)	12 (36%)	
	2 year college/tech. school	4 (19%)	6 (18%)	
	4 year college graduate	4 (19%)	8 (24%)	
	Any post-graduate work	5 (24%)	5 (15%)	
Parent/guardian literacy in medicine	7th to 8th grade	1 (5%)	1 (3%)	1.00
	≥9th grade	20 (95%)	32 (97%)	
Parent/guardian subjective numeracy	High numeracy	7 (33%)	9 (27%)	0.45
	Average numeracy	10 (48%)	21 (64%)	
	Low numeracy	4 (19%)	3 (9%)	
Caregiver psychological distress	Serious mental illness	2 (10%)	2 (6%)	0.64

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

Table 3

Between group differences.

Outcome	Control group Mean (SE) ($n = 21$)	Intervention group Mean (SE) ($n = 33$)	Intervention – control difference[a]	95% CI	p[b]
OPTION score	31.2 (3.7)[c]	43.8 (5.6)	12.6	(8.4, 16.8)	<0.01
Parent knowledge quiz (items correct)					
Intervention specific (11 items)	6.40 (0.49)	8.11 (0.28)	1.72	(0.59, 2.85)	≤0.01
Not in intervention (4 items)	2.71 (0.19)	2.93 (0.19)	0.22	(−0.37, 0.81)	0.47
Decisional conflict scale total score	16.2 (2.8)	10.7 (1.6)	−5.5	(−11.2, 0.3)	0.06
Visit duration (min)	41.0 (9.1)[c]	41.6 (9.9)	0.6	(−3.4, 4.8)	0.75
Prescription no. days covered	72.7 (3.4)	70.0 (1.6)	−2.7	(−9.4, 3.9)	0.42

CI = confidence interval.

[a] All means are adjusted to account for clustering within physician.

[b] p-Value for testing difference in means.

[c] One subject without video ($n = 20$).

Table 4

Between group differences.

Follow-up measure	**Control group No. (%)**	**Intervention group No. (%)**	***p***
≥1 Medication dosage tried in first 3 months	13 (62%)	25 (76%)	0.28
≥1 Follow-up visits (versus none)	10 (48%)	23 (70%)	0.20
≥1 Parent Vanderbilt assessment	5 (24%)	13 (39%)	0.36
≥1 Teacher Vanderbilt assessment	5 (24%)	9 (27%)	0.83
	Median (IQR)	Median (IQR)	*p*
Number of follow-up visits	0 (0,1)	1 (0,1)	0.08
Number of follow-up calls	0 (0,1)	1 (0,1)	0.08

IQR, interquartile range. All comparisons are adjusted to account for clustering within physician.

Table 5

Physician acceptability of medication choice cards.

Characteristic	***N* (%)**
Helpfulness of information	
Extremely helpful (6–7)	5 (71)
Somewhat helpful (3–5)	2 (29)
Not helpful at all (1–2)	0
Would recommend to others	
Yes (6–7)	6 (86)
Not sure (3–5)	1 (14)
No (1–2)	0
Would want to use for other decisions	
Yes (6–7)	3 (43)
Not sure (3–5)	4 (57)
No (1–2)	0