Published in final edited form as:

Expert Rev Neurother. 2011 April ; 11(4): 579–588. doi:10.1586/ern.10.151.

Promoting productive interactions between parents and physicians in the treatment of children with attention-deficit/hyperactivity disorder

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Abstract

Attention-deficit/hyperactivity disorder (ADHD) is a common neurobehavioral condition that impairs functioning throughout childhood and adolescence. Evidence-based guidelines for the treatment of ADHD recommend recognizing ADHD as a chronic condition. The chronic care model for child health emphasizes the need for productive interactions between an informed, activated family and a prepared, proactive practice team. Key parent–physician interactions in the treatment of a child with ADHD include: family education, treatment goal setting, treatment plan formation, cardiovascular screening, medication titration and ongoing monitoring and treatment plan revision. Most care for children/adolescents with ADHD is provided in community-based primary care settings where there are significant barriers to delivering high-quality care to children with chronic conditions. This article reviews recommended physician–parent interactions, examines current practice patterns and identifies facilitators and barriers to the implementation of recommended practices for ADHD care.

Keywords

attention-deficit/hyperactivity disorder; chronic care model; participatory/shared decision-making; physician–patient/parent communication; primary care; quality improvement

Attention-deficit /hyperactivity disorder (ADHD) is a common neurobehavioral condition [1] that results in impairment of academic, social and family functioning. Up to 90% of youths with ADHD remain functionally impaired as they enter adulthood [2]. Effective treatments, as well as evidence-based guidelines, for ADHD care have been developed [3,4]. Treatment guidelines from the American Academy of Pediatrics (AAP) and the American Academy of Child and Adolescent Psychiatry (AACAP) were both developed based on formal review of the evidence, as well as expert consensus. Owing to the developmental stability of ADHD throughout childhood and into adulthood, these guidelines emphasize the importance of recognizing ADHD as chronic condition. A critical feature of chronic care for child health is the need for productive interactions between an informed, activated family and a prepared, proactive practice team (Figure 1) [5].

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Financial & competing interests disclosure

The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

Specifically, there are a variety of aspects of ADHD chronic care described in ADHD treatment guidelines [3,4] that require productive interactions between parents and physicians. These interactions include:

- Family education
- Treatment goal setting
- Treatment plan formation
- Cardiovascular screening
- Medication titration
- Ongoing monitoring and treatment plan revision

The purpose of this article is to identify recommended physician–parent interactions for each of these aspects of ADHD care, examine current practice patterns and identify facilitators and barriers to the implementation of recommended practices for ADHD care. This synthesis of information will hopefully inform future intervention and dissemination efforts to promote productive interactions between parents and physicians in the care of children and adolescents with ADHD.

Study identification

Studies included in this article were found in the Medline and PsychInfo databases by cross-referencing the terms ‘attention deficit hyperactivity disorder’, ‘attention deficit disorder’ and ‘ADHD’ with key terms, including ‘treatment’, ‘management’, ‘guideline’, ‘chronic care’, ‘primary care’, ‘physician’ and ‘communication’. Articles were limited to those describing or intervening on care provided in community-based settings. Among included articles, a secondary review of cited references was performed.

Family education

Attention-deficit/hyperactivity disorder treatment guidelines recommend that physicians educate families about ADHD as an initial stage of the treatment process [3,4]. The AAP recognizes the need to provide information prior to discussing treatment options, as well as periodically monitoring and updating family knowledge and understanding. The AAP also states that the primary care provider should be available to answer family questions and should provide necessary information directly or in collaboration with community resources (e.g., mental health providers and/or family support groups). Unfortunately, there is no ‘gold standard’ approach to guide primary care providers in their efforts to meet families’ educational needs. The AAP developed a toolkit of resources for primary care providers. The toolkit includes educational materials to distribute to families. Parent materials cover general (e.g., ‘Understanding ADHD’ brochure) and specific topics (e.g., parenting strategies, homework strategies, educational rights and approaches for working with your child’s school). However, there are no published reports documenting either the extent to which parents are receiving these materials or their effectiveness. Similarly, a psychoeducation program for children with ADHD has been described [6]. This educational program has been incorporated into care delivered by psychiatrists and their clinical assistants. Outcome assessment of this program was limited to the extent that families used and were satisfied with materials during a pilot study. Families had a median of six educational contacts (mean duration 16.5 min) with a psychiatrist or clinical assistant and most materials were received by the majority of families. Among those who responded to the satisfaction questionnaire (response rate of 51% for parents and 41% for children/adolescents), 63% reported having received the right amount of information. Other educational resources for ADHD have been developed by organizations such as Children

and Adults with Attention-Deficit/Hyperactivity Disorder [101] and the National Institute of Mental Health [102]. These resources are available for free, but evidence for the use and/or impact of these resources in community settings is lacking.

Given the high prevalence of ADHD (e.g., 8.7% of school-age children [1]), its persistence throughout childhood and the limited availability of child mental health providers (i.e., psychologists and psychiatrists), most children and adolescents with ADHD are managed in primary care settings [7–9]. Research has demonstrated that primary care pediatricians report that they provide families with information on ADHD and a variety of relevant topics, including school modifications, organizational skills, consistency in parenting, structured activities, educational rights, self-esteem issues for the child and parental self-care [10]. There are few gauges of the quality of these interactions. Toomey *et al.* recently reported on parent-perceived quality of interactions with their physician using the results of the National Survey of Children with Special Health Care Needs (2005–2006), which contains a sample representative of the US population [11]. Among the 11,674 parents of children with ADHD surveyed, parents reported that their child's physician 'usually' or 'always' 'provides needed information' (79% of parents), 'spends enough time' (78% of parents), 'listens carefully' (87% of parents) and 'is culturally sensitive' (88% of parents). Among 6030 parents of children with ADHD surveyed for the National Survey of Children's Health in 2003, 69% of parents reported that their child's physician 'usually' or 'always' 'communicates well' [12]. Similarly, Hart *et al.* surveyed 801 parents of children with psychosocial problems about the quality of interactions [13]. A total of 61% of parents reported that their child's doctor always understands what the parent says or asks and 71% of parents reported that their child's doctor always answers questions in a way that the parent could understand.

Despite physician reports of educational efforts and parent reports that a majority of physicians have effective communication skills, unmet family educational needs probably persist. Leslie *et al.* found unmet educational needs among parents across all socio-economic and racial/ethnic groups who received ADHD care from practices participating in an ADHD improvement project in San Diego (CA, USA) [14,15]. This is not surprising given the many challenges to satisfying these needs. At the time of diagnosis, many parents are stressed and/or experiencing a variety of emotions [16]. This may impede parents' ability to receive, process and retain information. Indeed, parents need time to digest and reflect upon information regarding their child's difficulties and to consider treatment options [17,18]. Parents also struggle to resolve conflicting information from lay and professional, formal and informal sources [18]. In addition, there is likely a large amount of variation in learner needs [19,20]. Research has demonstrated that conceptualizations of ADHD (e.g., beliefs about cause, course and control) may differ among parents [16,17,21–24] and this can be a source of conflict between mothers and fathers [23]. Lack of congruence between parent conceptualizations and the biomedical model for ADHD can also lead to conflict with healthcare providers [14,17]. There is also a large amount of variation in learner styles and preferences for different formats and media [17,19]. Leslie *et al.* found that community clinics required different resources in comparison with private offices [25]. Compared with the private offices, community clinics served patients that were more likely to be from low-income (annual household income <US\$60,000: private office = 45% vs community clinic = 92%), publicly-insured (5 vs 89%), minority (18 vs 42%), single-parent (28 vs 50%) households. Educational materials needed to be low reading level, non-internet-based and bilingual. In addition, there was a preference for face-to-face education sessions (instead of reading materials/internet). Meeting the needs of individual learners is especially challenging for primary care providers who perceive a lack of time to deliver the needed education in the office and a lack of community resources to assist in meeting this need [15]. Facilitators of family education include extending the time allotted for ADHD visits [10,26],

scheduling visits at the end of the day [10,15] and having appropriate materials to augment physician efforts [15,25].

Treatment goal setting

The AAP ADHD treatment guideline recommends that the treating clinician, parents and the child, in collaboration with school personnel, should specify appropriate target outcomes to guide management [3]. Treatment goal setting is an important component of family/self management. To date, only two studies have reported the degree to which primary care providers are implementing this recommendation. Both studies collected baseline performance in preparation for an intervention to improve practice. Few physicians documented goals set with the family in the medical record, with a range of 1% [27] to 39% [28] of audited encounters. It is unclear whether goals are being discussed during clinical encounters but not documented. Documentation of goal setting is facilitated by providing physicians with training and a documentation template that prompts this activity. The AAP toolkit includes an ADHD written care-management plan template that includes goal setting. This tool, or adaptations of it, has been included in quality improvement interventions [27,28]. The Homer *et al.* intervention did not demonstrate improvements on this outcome, although there was improvement in both intervention and control groups [28]. Epstein *et al.* found that initial uptake of the written care-management plan was robust, with all audited encounters over the first 3 months of the intervention having a plan [27]. However, at 12 months, performance declined to 53% of audited encounters. Epstein *et al.* did not comment on specific barriers and facilitators of sustained use of a written care-management plan [27].

Treatment plan formation

Attention-deficit/hyperactivity disorder treatment guidelines state that, based on the research evidence, physicians should recommend stimulant medication and/or behavior therapy [3,4]. This guidance is based, to a large extent, on the findings of the Multimodal Treatment Study of Children with ADHD (MTA) [29]. At the end of the 14-month trial, the proportion of children whose ADHD symptoms 'normalized' was 68% in the multimodal combination group, 56% in the MTA medication algorithm alone group, 34% in the intensive MTA behavior therapy algorithm alone group and 25% in the community control group [30]. While the chance of behavior 'normalization' varies across the four treatment conditions, so too do the potential downsides of treatment (e.g., costs and harms). As a result, the treatment guidelines also recognize the importance of taking family goals, preferences, cultural values and concerns into account when developing a treatment plan [3,4]. Partnership with the family, also referred to as therapeutic alliance (i.e., formation of a working relationship around shared goals and processes of treatment), is seen as essential to success in the long-term care of children with ADHD [3].

Estimates of the treatment options recommended/offered by physicians vary. Among primary care providers in Michigan (USA), two-thirds reported recommending medications and just over half reported recommending behavior therapy to parents of children diagnosed with ADHD [31]. In another study, pediatricians reported offering either a medication or behavior therapy treatment 91% of the time, but only offered both medicine and behavior therapy half of the time [28]. One study suggests that physicians are more likely to recommend a treatment modality when the physician perceives parents will agree with the treatment recommendation [32]. There are no physician reports regarding the degree to which complimentary and alternative medicine (CAM) treatments are recommended/offered. Despite limited evidence for the benefit of any CAM treatment for ADHD [33], research from the USA [34], Canada [35] and Australia [36] suggest that a majority of

parents of children with ADHD use CAM. Despite this, only 11% of parents reported discussing CAM therapies with their child's doctor [34].

Primary care physicians in North Carolina (USA) reported that they use a participatory decision-making style with parents of children with ADHD 88% of the time [37]. Similarly, 85% of parents of children with ADHD reported that their child's doctor helps them feel like a partner in care 'usually' or 'always' [11]. By contrast, Hart *et al.* found that 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 for a child [13]. In this study, parents who were involved in treatment planning were almost unanimously 'very satisfied' and four-times more likely to rate quality of care as very high. In Australia, the most common reasons for dissatisfaction among parents of children with ADHD were the perception that the child's doctor was only interested in prescribing medicine and that the doctor did not understand the child's problem [36]. To date, all published descriptions of interactions during ADHD treatment planning have been based on family or physician report. There have been no studies using direct observation of parent-child-physician interactions that directly examine patterns of interaction during treatment planning.

At the time of diagnosis, parents view behavioral therapy as a more acceptable option than medication [38,39] and/or have a general reluctance to use medicine for ADHD [16,40]. However, many parents feel that they have exhausted parenting approaches and must resort to trying medication [16,18]. Inclusion of medication in the treatment plan is also facilitated by parent acceptance of the diagnosis of ADHD [14,16,21,23], recognition of their child's functional impairments [16,41], and support for medicine use from members of family and/or extended social networks [14,16–18,23]. Barriers to inclusion of behavioral therapy in the treatment plan may include physicians not having a prominent role in the delivery of behavior therapy [31] and/or encountering difficulties when attempting to procure behavior therapy services from the school and mental health sectors [25,42]. For parents, treatment planning can feel like a balancing act, with their goals for the present/future being weighed against concerns regarding the side effects and possible long-term effects of medication [16,18,43]. Parent trust in their child's doctor appears to be a key facilitator of parent engagement in the treatment planning process [14,16]. Lack of trust in physicians during the ADHD treatment-planning process has been reported to be more common among minorities [14,44,45]. Physicians presenting initiation of medication to parents as a time-limited trial is viewed by parents as an engaging behavior [16,18].

Cardiovascular screening

In 2008, the AAP issued a policy statement entitled, 'Cardiovascular Monitoring and Stimulant Drugs for Attention-Deficit/Hyperactivity Disorder' [46]. This statement recommends that physicians obtain from parents a targeted cardiac history (e.g., patient history of previously detected cardiac disease, palpitations, syncope or seizures; and family history of sudden death in children or young adults; hypertrophic cardiomyopathy and long QT syndrome) and conduct a cardiac physical examination. There are no reports regarding the degree to which these recommendations have been implemented in practice. However, Conway *et al.* found that Canadian physicians reported an increase in screening for cardiac disease among children treated for ADHD after Health Canada advised against the use of stimulants in children with cardiac disease [47]. Physicians reported more frequently asking about patient history of congenital heart disease (42% pre- and 96% post-advisory statement) and family history of sudden death (23% pre- and 81% post-advisory statement). Therefore, release of an advisory by a prominent health organization and coincident media coverage appear to be facilitators of implementing cardiovascular screening in Canada.

Medication titration

Owing to significant individual variation in response to stimulant medications, a systematic titration is needed to identify the optimal medicine and dosage for each child. The gold standard approach to titration is the N-of-1 trial (e.g., double-blind within subject trial of stimulant medication at a range of dosages and placebo) [48,49]. While N-of-1 trials have been implemented as part of referral/consultative models of care [50–52] and parents report high levels of satisfaction with N-of-1 trials [52–54], such trials lack feasibility in primary care settings [50]. As a result, ADHD practice guidelines recommend open-label upward titration of stimulant medication every 1–3 weeks until ADHD symptoms remit or side effects prevent further titration. The AACAP recommends that parent and teacher ratings of symptoms and side effects should be obtained after the child has been on a particular dose for at least 1 week and overall progress should be reviewed during an office visit after the first month of treatment [4]. Providing anticipatory guidance and close monitoring is important as side effects are a common reason for medication discontinuation in the first few months of treatment [55]. In the USA, the National Committee for Quality Assurance Healthcare Effectiveness Data and Information Set (HEDIS) has defined quality ADHD care during the medication-initiation phase as the percentage of patients 6–12 years of age with an ambulatory prescription dispensed for ADHD medication who had one face-to-face follow-up visit with a practitioner with prescribing authority within 30 days after the start date on their first prescription [103]. In 2008, approximately 35% of children received this level of care. There has been very modest improvement in this quality measure over the past 4 years (~32% in 2005 to ~35% in 2008) [103]. Performance has been similar across commercial and Medicaid-managed care organizations [103]. Quality improvement intervention (e.g., ADHD Collaborative) has been demonstrated to markedly increase the proportion of children with: office contact within 14 days of starting medicine (27% pre-intervention to 57% after 12 months in the ADHD Collaborative); and an office visit within 6 weeks of starting medicine (52 increased to 64%), as well as improve follow-up parent (9 increased to 30%) and teacher (9 increased to 26%) ratings obtained within 6 weeks of starting medication [27]. Despite these significant increases, there still remains room for improvement in this area.

Both physician practice behavior and families' adherence make the titration process difficult. Using physician self-report, over 80% of primary care providers report titrating medicine and having follow-up within 1 month [31]. However, using chart reviews, 27% of children with ADHD had office contact (e.g., visit, telephone or email) within 14 days of starting medicine and 52% had an office visit within 6 weeks of starting medicine [27]. Furthermore, 9% of patients had follow-up parent and teacher ratings obtained within 6 weeks of starting medicine to evaluate response [27]. On the family side, a significant minority (~25%) of parents do not adhere to physician prescribing instructions during initial titration [56,57]. Moreover, many do so without informing their child's doctor [58]. There appears to be a need for better physician–family communication, as well as close proactive follow-up during medication titration. A common barrier to trying a full range of dosages is family resistance to increasing the dosage after seeing improvement in their child's behavior on the initial (e.g., lowest) dose [59]. Prior to starting medication, physicians should provide anticipatory guidance to parents about the need to try a range of dosages to find the optimal dosage. Parental trust in their child's physician is essential for titration to be successful.

Ongoing monitoring & treatment plan revision

Attention-deficit/hyperactivity disorder treatment guideline recommendations [3,4] for ongoing monitoring are largely based on findings from the MTA study [29]. MTA protocols for ongoing monitoring of medication were far more rigorous and intensive than care

provided by community-based primary care providers at the time of the study. Physician follow-up visits were longer (MTA: 30 min vs community control group: 18 min) and more frequent (MTA: 8.8 visits per year vs community control group: 2.3 visits per year) [30]. Based on MTA intervention protocols, teachers were contacted monthly by telephone to obtain feedback to optimize medication regimens. Medication adjustments were common, with 71% of subjects having at least one change and an average of two medicine/dosage changes per subject over the 14-month study [60]. Unfortunately, no studies have systematically varied conditions (e.g., frequency and type of contact) to determine whether outcomes similar in effect size to the MTA can be obtained with less intensive monitoring. As such, ADHD treatment guidelines provide rather general recommendations in this area. The AAP acknowledges that the frequency of monitoring depends on the degree of dysfunction [3]. Once a child is stable, the AAP recommends an office visit every 3–6 months to allow for the assessment of learning, behavior and adherence to the treatment plan. The AAP also recommends a wide range of methods to obtain information about progress on target symptoms. These methods include office interviews, telephone conversations, teacher narratives, periodic behavior report cards and behavioral ratings [3]. The AACAP recommends that follow-up should occur “at least several times per year” [4]. Treatment for ADHD should continue as long as symptoms remain present and cause impairment. If there are no symptoms for 1 year; a trial of being off medication should be considered to help determine whether there is a continued need for medication [4]. HEDIS has defined quality follow-up for children prescribed ADHD medication as the proportion of children who receive a medication supply sufficient to cover at least 210 of the first 300 days of treatment and have at least two follow-up visits in the 9 months subsequent to the initiation phase [103]. One of these two visits can be a telephone visit with a practitioner [103]. In 2008, approximately 40% of children received this level of care. Performance was similar across commercial and Medicaid-managed care organizations [103].

Research indicates that most children treated for ADHD eventually discontinue treatment either by stopping altogether or periodically stopping and re-starting medicine. For example, 80% of children have a gap in medication supply of 1 month or more within the first year of treatment and only half of these children will re-start medication within 90 days [56]. Parents continue to experience fears and worries related to the potential for long-term adverse effects, even if their child shows marked improvement [16–18,43,61]. These findings underscore the importance of ongoing monitoring. Analysis of the 1997 Medical Expenditure Panel Survey, which is a representative sample of the US population, demonstrated a frequency of follow-up (2.4 physician visits per year) that was similar to the community control group in the MTA study [62]. In Michigan (USA), just over half of the primary care physicians surveyed reported evaluating medications three- to four-times per year [31]. In Australia, parents were more likely to be satisfied or very satisfied with ADHD care if follow-up appointments were more frequent than every 6 months [36]. Analysis of the National Survey of Children with Special Health Care Needs (2005–2006) demonstrates that less than half of US parents of children with ADHD are satisfied with communication between their child’s doctor and their child’s school [11]. In total, 59% reported receiving as much help as needed coordinating care [11]. There are no reports regarding how effectively information obtained during ongoing monitoring is used by parents and physicians to optimize the treatment plan in community-based primary care settings. Likewise, there are no estimates for the frequency of physician-coordinated, AACAP recommended trials of a patient being off medication to help determine continued need [4]. Qualitative research suggests that trials of a patient being off medicine are often parent- or child-initiated [16].

Barriers to ongoing monitoring include the logistical challenges of getting information to and from parents and teachers [50], which may be more significant in urban rather than suburban settings [25,42,63]. Lack of physician time and/or reimbursement for care

coordination efforts is another barrier [50]. In addition, higher severity of ADHD has been associated with a lower likelihood of receiving coordinated care [11]. Despite robust improvements in many physician behaviors, Epstein *et al.* found ongoing monitoring of treatment to be more difficult to change than assessment behaviors [27]. There was a significant drop-off in the number of parent and teacher behavioral ratings that were obtained by physicians over time [64]. At diagnosis, 785 children had both parent and teacher ratings, but this number declined as follows: 1 day to 3 months: parent 69% (n = 539), teacher 67% (n = 528); 3–6 months: parent 29% (n = 224), teacher 29% (n = 225); 6–9 months parent 19% (n = 148), teacher 17% (n = 130); and 9–12 months: parent 11% (n = 84), teacher 11% (n = 86). It is not clear to what extent this phenomenon was driven by physicians making a conscious decision to not obtain further ratings after children had demonstrated symptom remission on a previous checklist. Furthermore, it is not known whether the decrease in ratings over time represents challenges for parents to maintain high levels of engagement/activation and/or practices to be proactive in their approach to follow-up.

Expert commentary

Attention-deficit/hyperactivity disorder treatment guidelines emphasize the importance of promoting productive interactions between an informed, activated patient and family with a prepared, proactive practice team in order to improve ADHD functional and clinical outcomes. Key parent–physician interactions include: family education, treatment goal setting, treatment plan formation, cardiovascular screening, medication titration and ongoing monitoring and treatment plan revision. The literature reviewed has several limitations. Methods and materials to help physicians meet the educational needs of families have not been tested. The extant literature on parent–physician interactions in the care of children with ADHD relies solely on parent and physician report rather than directly observed or audio/video recorded encounters. In addition, research has focused almost exclusively on face-to-face interactions. The role of telephone and/or email communication between parents and physicians has not been described. There has also been little attention to the role of children/adolescents in the treatment process, as well as the role of parent and/or physician interaction with teachers.

Five-year view

Key interactions among parents and physicians in the treatment of children with ADHD have been identified. In the next 5 years, the following gaps in the current literature will be filled in order to advance efforts to promote productive interactions to optimize care for children with ADHD.

Develop & test educational interventions

Family knowledge about ADHD and treatment options is a prerequisite for parent participation in goal setting and treatment plan formation. However, meeting family educational needs is a significant challenge in primary care settings. Every parent is unique and brings different knowledge, attitudes and preferences to the medical encounter with their child's doctor. Currently, there are no established tools to help assess parent learning needs. Such tools are needed for family education efforts to move beyond a 'one-size-fits-all' approach. Tailoring educational content and methods to the individual learner holds the potential to more efficiently and effectively meet educational needs. In addition to addressing identified knowledge gaps, it may prove important to tailor educational efforts based on parental conceptualization of ADHD, parent readiness to set goals and/or develop treatment plans, and/or the lack of congruence between parents in these areas. In addition, educational materials, choice of media and delivery methods need to be tested. Such efforts

should include parents with a range of education and literacy/numeracy levels. Moving forward, efforts to improve family education should be strategically embedded in the process of care to ensure that families get the right information, at the right time, in the right way. Quality improvement methods that focus on changing the system of care will be needed in order to ensure that family education is delivered reliably.

Direct observation

While parent and physician reports regarding interactions in the treatment of ADHD are important and useful, direct observation of these behaviors will be essential to move the field forward. Analysis of audio and/or video recorded encounters between parents and physicians will help answer the following questions. To what extent does goal setting occur, but fail to get documented? To what extent are physicians presenting options and discussing the pros and cons of each? To what extent are parent preferences and values elicited? When developing treatment plans, to what extent are parents and physicians engaging in a participatory or shared decision-making (SDM) process? To what extent are physicians demonstrating behaviors that promote therapeutic alliance and partnership with parents? How frequently are physicians completing the recommended cardiovascular screening prior to starting stimulant medications?

Develop & test interventions to support parent involvement in treatment plan formation

Opportunities exist to develop and test interventions to support productive interactions over time between parents and physicians. For example, SDM is a process that facilitates clinical decisions that are both evidence-based and value sensitive. Practitioners communicate information on options and outcomes, and patients/parents communicate the personal value they place on the benefits versus harms so that agreement on the best strategy can be reached. However, barriers exist to implementing SDM in practice: physicians are challenged with time pressures and providing up-to-date evidence-based information that is understandable in terms of literacy and numeracy, while families often need help communicating what is important to them. Patient/parent decision aids are practical tools that facilitate SDM by augmenting physician communication with pictures and words to provide objective information on the probabilities of benefits and harms of treatment options and help people to clarify their personal values so that a more informed and personally congruent decision can be made. A systematic review of 55 randomized controlled trials of decision aids demonstrates that they consistently improve decisional quality [65]. Patients know more, have more realistic expectations for outcomes, experience less uncertainty about their choice and participate more in decision-making. However, to date, SDM and decision aids have not been well studied in pediatrics and no study has examined the effect of implementing such an intervention among parents of children with ADHD. SDM may help to eliminate documented disparities in ADHD care, as there is some evidence that medication treatment preferences vary across racial and ethnic groups [45,66].

Develop & test interventions to support ongoing monitoring & communication

Ongoing monitoring requires that parents maintain high levels of engagement/activation over time and that practice teams are prepared and proactive in their approach to follow-up. This may be especially challenging for both parties. Parents often juggle competing demands for their attention and may struggle to remain vigilant in the absence of a child crisis. Practice teams historically are very prepared to respond to requests when approached by parents, but struggle to keep families on their radar in the absence of family-initiated contact. It is uncommon for primary care practices to have case managers or surveillance systems in place to notice when a parent/patient fails to act (e.g., request a refill, schedule a follow-up appointment, or notify regarding a change in symptoms or side effects). Technology may help parents and practice teams overcome these barriers as patient

registries and internet-based patient portals have been a useful tools in the management of other chronic medical conditions. Registries vary in structure (e.g., single practice, multipractice, health system and national) and content (e.g., medical record, laboratory results, visit claims and pharmacy claims). On the system level, registries can aggregate data to monitor the performance of a care system. On the individual level, registries can help practice teams to track, case manage and coordinate care for individual patients. Patient portals can serve as a repository for monitoring data (e.g., behavioral ratings and other target outcomes) and facilitate communication between all members of the care team. For the child with ADHD, this may include teachers, as well as parents, physicians, psychologists and others. Communication that is not reliant on a face-to-face visit may help to promote productive interactions over time.

Quality measurement

The established HEDIS quality measure for the ADHD medication initiation phase has significant limitations. The initiation phase measure does not attempt to assess whether a range of dosages have been tried. This is a key determinant of titration quality. In addition, the time frame of interest (e.g., face-to-face follow-up within 30 days for medication initiation) is somewhat arbitrary and has not been endorsed in either treatment guideline [3–4]. The initiation phase measure does not recognize telephone and/or email correspondence as legitimate modes of communication. There is strong evidence supporting the use of telemedicine in support of adults with chronic conditions [67,68], but it has not been studied in the treatment of children with ADHD. Emerging evidence from quality improvement projects, such as the ADHD Collaborative [27,64], may help inform revision of this quality measure. For example, physicians involved in the ADHD Collaborative intervention reliably had telephone contact with families within 14 days of starting medicine and an office visit within 6 weeks (rather than 30 days) of starting medicine [27] and achieved outcomes comparable to the MTA study (e.g., child symptom reduction effect size [Cohen's *d*] of 1.45 for parent ratings and 1.47 for teacher ratings) [64].

Reimbursement

Similar to quality measurement, current reimbursement practices are largely focused on care delivered during face-to-face visits. This creates barriers for practice teams to provide aspects of high-quality chronic care that exist outside of visits, such as care coordination and ongoing monitoring. Such services are difficult to sustain without reimbursement to support the necessary infrastructure. In 2009, the AAP and AACAP issued a joint policy statement entitled, 'Improving Mental Health Services in Primary Care: Reducing Administrative and Financial Barriers to Access and Collaboration' [69]. Recommendations included support payment for non-face-to-face aspects of care, such as care coordination and communication with community providers. In addition, the statement endorsed support payment for sessions with parents without the patient present, including those non-face-to-face services and support for treatment planning and treatment team meetings that may not include the patient, or at times, even family members. While there are billing codes for all of the non-face-to-face interactions described previously, reimbursement for these services is highly variable.

Key issues

- Attention-deficit/hyperactivity disorder (ADHD) is a common neurobehavioral condition that impairs functioning throughout childhood and adolescence.
- Evidence-based guidelines for the treatment of ADHD recommend recognizing ADHD as a chronic condition.

- The chronic care model for child health emphasizes the need for productive interactions between an informed, activated family and a prepared, proactive practice team.
- Key parent–physician interactions in the treatment of a child with ADHD include: family education, treatment goal setting, treatment plan formation, cardiovascular screening, medication titration and ongoing monitoring and treatment plan revision.
- Most care for children/adolescents with ADHD is provided in community-based primary care settings where there are significant barriers to delivering high-quality care to children with chronic conditions.
- Based on the current performance documented, there is room to improve parent–physician interactions in the treatment of ADHD.
- Quality improvement interventions that focus on modifying the healthcare delivery system show promise in improving interactions, as well as child outcomes.
- Additional interventions are needed to promote productive interactions between parents and physicians. These may include tailored family education systems, decision aids to augment physician communication, patient portals to facilitate ongoing monitoring, refined measures of ADHD care quality and re-aligned reimbursement practices to promote high-quality care.

Acknowledgments

William Brinkman is supported by a Mentored Patient-Oriented Research Career Development Award from the National Institute of Mental Health (K23 MH083027). Jeffery Epstein is supported by a Mid-Career Investigator Award in Patient-Oriented Research from the National Institute of Mental Health (K24 MH064478). Jeffery Epstein also receives research funding from Eli Lilly & Company.

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Figure 1.
Chronic Care Model for Child Health.