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# Coordinating systems of care using health information technology: development of the ADHD Care Assistant

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#### ABSTRACT

Perhaps the two principal venues for the delivery of mental health services are schools and primary care practices. Unfortunately, these systems of care are poorly connected, which may result in care that is fragmented and suboptimal. This article describes the development and implementation of an electronic health record portal, known as the ADHD Care Assistant, to facilitate the sharing of information between schools and primary care offices to promote the use of evidence-based practices for managing children with behavioral health conditions. A feasibility study was conducted across 19 diverse primary care practices with 105 participating providers. Across the practices, 67% of providers activated the system for at least one patient and 32% activated it for five or more cases. Care Assistant use was lower in practices with a relatively high percentage of Medicaid patients ( $\geq$ 25%). The article discusses challenges that have arisen among primary care providers, parents, and schools in using the Care Assistant, potential strategies for addressing the challenges, and directions for future research and practice.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Primary care; schools; coordination; information technology; ADHD

Utilization of mental health services by children and families is a major public health concern. Although it is estimated that each year between 15 and 25% of children and youth experience an emotional or behavioral disorder (Costello, Egger, & Angold, 2005; Merikangas et al., 2010), only 20–50% of those with serious conditions receive needed services (Costello, 2009). Substantial disparities in service use have been identified; children who are poor and those of minority racial/ethnic background generally utilize mental health services significantly less than those who are more advantaged or non-minority (Samnaliev, McGovern, & Clark, 2009; Wang et al., 2005).

Numerous factors contribute to underutilization of mental health services. One set of factors are structural barriers reducing access to care, which include scheduling difficulties, transportation challenges, financial costs, and poorly coordinated services. In addition, psychological barriers can limit care; these factors include the stigma of mental health services, lack of trust in the mental health system and providers, and lack of parental self-efficacy in

navigating the mental health system (Owens et al., 2002; Power, Eiraldi, Clarke, Mazzuca, & Krain, 2005).

#### Improving access to mental health care: behavioral health in primary care

Many strategies have been proposed to improve utilization of mental health services (Eiraldi, Mazzuca, Clarke, & Power, 2006; Isaacs et al., 2008). A rapidly emerging strategy is to build the capacity of pediatric primary care providers (PCPs) to address children's mental health needs, which has been strongly supported by the American Academic of Pediatrics (AAP; Foy, Perrin, and the American Academy of Pediatrics Task Force on Mental Health, 2010). Resources and training guides have been developed to support pediatric PCPs in this expanded role (AAP, 2010). Training and supporting PCPs to provide mental health services has numerous potential advantages. First, integrating mental health and medical care may reduce the stigma often associated with mental health services. Second, this strategy may enhance patient and family trust by associating mental health service delivery with trusted PCPs. Third, with the increasing adoption of the medical home model in primary care, which is strongly encouraged by the Patient Protection and Affordable Care Act, providing mental health services in the context of primary care promotes coordination of service delivery (AAP, 2002). Fourth, given the accessibility of primary care, supporting PCPs to offer mental health services can promote the delivery of timely mental health care in a familiar place.

#### Importance of linking primary care practices and schools

PCPs experience several challenges in addressing the mental health needs of children (Leslie, Weckerly, Plemmons, Landsverk, & Eastman, 2004). A common challenge is finding the time to conduct an assessment, provide adequate follow-up care, and collaborate with professionals in the community, given the limited time available for typical primary care appointments. Another challenge is coordinating efforts with school professionals (Guevara et al., 2005), which is critically important, given that primary care and school are the principal venues for mental health service delivery in this country (Power, Blum, Guevara, Jones, & Leslie, 2013). Coordinating communications necessitates the sharing of health information and educational information, which are highly regulated in order to protect privacy (i.e. Health Information Portability and Accountability Act [HIPAA]; Family Educational Rights and Privacy Act [FERPA]). In addition, arranging for primary care and school providers to communicate typically poses major scheduling challenges. Further, differences in the training, conceptual models, and language used by health and educational professionals may contribute to communication problems between them (Leslie et al., 2004). Not surprisingly, PCPs' success in obtaining teacher ratings for initial evaluations of behavioral health problems, such as attention deficit/hyperactivity disorder (ADHD), is highly variable and generally poor (Epstein et al., 2010). Further, PCPs' success in obtaining teacher input for follow-up care is generally extremely poor (Epstein et al., 2014).

Lack of coordination between primary care practices and schools poses several problems in caring for children with mental health needs. At the most basic level, providers in these settings experience major challenges with the exchange of information that is needed for assessment and treatment. In addition, there is typically little if any collaboration between systems to develop intervention plans and coordinate treatment implementation (Power et al., 2013). Further, progress monitoring is highly limited, which makes it difficult to make adjustments in intervention plans when indicated (Epstein et al., 2014). Unfortunately, parents are generally placed in the position of coordinating communications among systems, which may be untenable for many families, especially those from lower income settings who are coping with multiple stressors and limited resources and parents who have ADHD themselves (Power et al., 2013).

Numerous models have been developed to improve the quality of mental health services offered in primary care. For example, consultation models have been developed to train PCPs in the skills needed to use evidence-based practices and collaborate effectively with schools and community agencies (Leslie et al., 2004). Also, learning collaboratives including PCPs, school professionals, and community advocates have been organized to develop methods of collaboration and shared protocols to promote evidence-based care (Foy & Earls, 2005). In addition, evidence-based psychosocial interventions have been implemented in primary care and the results of these efforts have been encouraging (Kolko et al., 2014; Silverstein et al., 2015). Further, behavioral interventions with an explicit focus on promoting family–school collaboration have been implemented with some success in primary care practices (Power et al., 2014). Although these models are promising, implementing and sustaining the use of these programs on an ongoing basis without external grant funding can be challenging (Epstein, Langberg, Lichtenstein, Kolb, & Simon, 2013).

#### Health information technology to improve ADHD care

Health information technology has the potential to improve cross-system communication, promote coordinated care in an efficient and sustainable manner, and has been widely recognized as a necessary foundation for improving the guality and outcomes of clinical care (Institute of Medicine, 2001). Toward this end, the federal Meaningful Use Program has allocated more than \$32 billion to support the implementation and optimizing of electronic health record systems (EHRs; Centers for Medicare and Medicaid Services, 2015). To lower costs and improve outcomes, the Meaningful Use Program increasingly recognizes the need to link EHRs with external sources of clinical information. Historically, such work has focused on the linkage of information across health care settings through Health Information Exchanges (Hersh et al., 2015). More recently, efforts have broadened to link data entered by patients through web-based portals or collected by devices, such as asthma-metered dose inhalers and glucose monitors for diabetes, into the EHR (Kruse, Bolton, & Freriks, 2015). However, such approaches do not capture the full range of information needed to provide evidence-based care for children with behavioral health conditions such as ADHD because information from schools has not been integrated with the clinical record. Even when Internet-based tools are available to obtain parent and teacher rating scales for ADHD (Epstein et al., 2013), the results do not appear within the EHR because these two electronic systems are not integrated. Finally, despite research and clinical practice guidelines documenting the importance of shared decision-making between clinicians and families regarding ADHD and the benefits of electronic decision support tools that foster shared decisionmaking in other settings (Fiks, Hughes, Gafen, Guevara, & Barg, 2011; Fiks et al., 2015), existing systems do not frame care around families' preferences and goals for treatment (Fiks, 2011).

## **Purpose of study**

This article describes the development of an electronic system to enable PCPs to obtain information from schools to foster the use of evidence-based services in managing children with behavioral health conditions. Although the major focus of the article is on ADHD, the principles and strategies discussed are likely applicable to a range of behavioral and emotional conditions for which obtaining teacher information is beneficial. A major purpose of the article is to present preliminary information about the feasibility of this electronic system and factors related to use of this tool in primary care practice. The article concludes with a discussion of strategies for addressing challenges in using technology to promote information exchange as part of care coordination as well as directions for future development.

## Method

#### History, development, and functionality of the ADHD Care Assistant

The work presented in this article builds upon a decade of work developing software known as the 'Care Assistant' to support clinical decision-making, streamline workflows, and improve outcomes in pediatric primary care settings. In 2004, members of our team recognized that vendor-provided clinical decision support (CDS) technologies were insufficient to support our informatics research and development activities at The Children's Hospital of Philadelphia. Prior to that time, researchers at our institution received extensive training from the vendor in an effort to learn possible ways to meaningfully customize CDS or workflow tools. Training and retaining such a specialized workforce were challenging, so we developed an alternative framework, the 'Care Assistant,' which enabled our researchers to work in familiar web development programming languages without any specialized training.

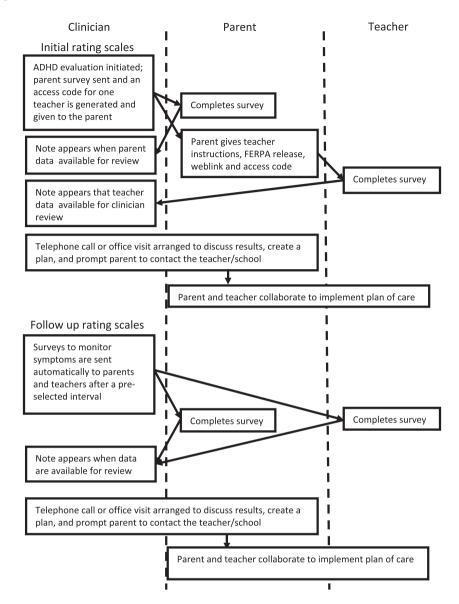
The Care Assistant was developed to address the limited functionality and flexibility of EHRs to organize pediatric health information and support clinical decision-making and workflows. The tool provides features that fall into two broad categories: data services and clinician tools. To facilitate communication with external applications, it provides access to EHR data and functionality through the use of web services, an industry standard for interapplication communication. This enables third-party tools to extract patient data, collect supplemental information when needed (for example, survey response data), and process this information outside the EHR. The data collected can then be incorporated into the EHR to supplement the patient record. To aide pediatric PCPs, who included pediatricians and pediatric nurse practitioners, the tool provides functionality to streamline workflows within the EHR by supporting order entry, documentation, access to knowledge resources, such as clinical practice guidelines, and communication both within the office and between the office and families. Prior implementations of the Care Assistant have supported research projects in diverse clinical domains including immunizations, asthma, otitis media, developmental surveillance, short stature, and prematurity (Fiks et al., 2012). Because Care Assistant interventions can dynamically link to web-based content, the tool has the flexibility to design custom software to best meet user needs and specifications, a critical goal given the importance of aligning software with workflows (Kawamoto, Houlihan, Balas, & Lobach, 2005).

The ADHD Care Assistant consists of three main components: an electronic survey tool (Research Electronic Data Capture [REDCap]; http://www.project-redcap.org/cite.php) to

collect data from parents and teachers; a module visible to providers integrated into the EHR; and a web service that facilitates communication between these two endpoints. This system or portal is designed to make information gathered via the electronic survey tool available to the PCP directly in the EHR. The ADHD Care Assistant allows providers to measure progress toward meeting goals and track clinical progress over time. In addition, this portal allows providers to adjust survey intervals as indicated to examine treatment effects and side effects. A second goal of the automated process is to avoid delay or the potential for documents to be misplaced during handoffs between parents, teachers, and the clinical team. To achieve these goals, the ADHD Care Assistant was developed in collaboration with parents, PCPs, and educators. To address HIPAA and FERPA requirements, legal experts provided additional guidance. Given that ADHD care offered by pediatric providers at our institution is considered medical care, information obtained through the ADHD Care Assistant is incorporated into the primary care EHR without special protections typically afforded to mental health information. To focus on the age group most commonly diagnosed with ADHD, the current version of Care Assistant was designed for children between the ages of 5 and 12 years.

Figure 1 describes the workflow for the ADHD Care Assistant, involving the primary care system (the PCP), the parent, and the teacher. Use of this portal begins with a conversation between the treating provider and parent/guardian (subsequently 'parent') regarding behavior. If parents agree to the use of the electronic system, a HIPAA release form is signed by the parent and collected annually for as long as Case Assistant use continues. The provider then activates the Care Assistant directly within the EHR. Upon activation, an email link to an electronic survey, which includes an assessment of family preferences and goals for treatment using a validated instrument (ADHD Preference and Goal Instrument; Fiks et al., 2012) as well as the initial Vanderbilt parent rating scale (Wolraich et al., 2003), is immediately sent to the parent. Receipt can be confirmed during the office visit and, if desired, the scale can be completed on the parent's smart phone and reviewed prior to the close of the clinical encounter. At the same time, forms are printed for the parent to hand to the teacher that contain a link to a teacher enrollment website and an access code to associate the teacher with the student. Upon enrolling, the teacher is then emailed a link to complete the initial Vanderbilt teacher rating scale (Wolraich, Feurer, Hannah, Baumgaertel, & Pinnock, 1998), which is linked to the child's EHR. Although not required by the PCP, a FERPA release form is also given to the parent to hand to the teacher along with these access codes. This release form was included because parents must provide authorization for teachers to share rating scale data directly with providers, and some teachers may not have a FERPA form readily available. This workflow for engaging teachers, as opposed to sending an email directly to them, was chosen based on feedback that not all parents have teachers' email addresses and not all teachers are comfortable with electronic communication with parents or providers. This approach also recognizes the parent's central role in approving the flow of information to and from the school during the evaluation and treatment processes.

Once rating scales are completed by the parent and/or teacher, they appear immediately within the EHR. The provider is notified by the system that the forms have been completed through an automated message with the child's name and summary scores that appear within the EHR. At this point, the provider is able to review the scores and follow-up with the parent to develop or refine a plan of care. Parents and teachers may then collaborate to implement and adapt the plan. Subsequently, at an interval agreed upon by the provider



#### Figure 1. This figure depicts the workflow of the ADHD Care Assistant.

Notes: Evaluation of ADHD in the clinical setting requires a series of actions to be completed by the clinician, parent, and teacher. Following completion of a HIPAA consent form, the Care Assistant is activated and a survey is generated by the clinician and sent directly to the parent. A form is given to the parent to share with the teacher that includes instructions, a FERPA release, the link to a teacher enrollment website, and a unique code to associate the teacher with a particular student. Completed surveys from parents and teachers return directly to the clinician for review. Return of the surveys often prompts a conversation between the clinician and parent to determine the plan of care. Parents and teachers then collaborate to implement the plan. The delivery of follow-up rating scales to parents and teachers is automated at an interval determined by the treatment team to promote ongoing collaboration. As can be seen, the workflow for each follow-up assessment is virtually identical to that of the initial assessment.

and parent, follow-up Vanderbilt rating scales are automatically sent to both parents and teachers and the provider is able to review results of the repeated measurements to assess clinical progress and tailor treatment in partnership with parents and teachers. Side effects of medication, as applicable, are also recorded and can be used to address issues that may

limit medication adherence or present safety risks. Both the teacher and parent provide information on side effects. The Care Assistant also includes links to web content to create tailored handouts for parents and teachers, which providers can distribute during the course of treatment and follow-up.

The screenshot in Figure 2 provides a summary of parent-reported preferences and goals for treatment obtained from the initial parent assessment as well as results from the Vanderbilt teacher rating scale for the initial and follow-up assessments. In this case of a second-grade student, the family indicated an intermediate preference for behavior therapy and strong preference for the use of medication in treating ADHD. With regard to goals, the family indicated that improving school performance and behavior were medium-level

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collection of goals for AD			ne parent and	teacher and the	e assessment	of preferences a
	e Survey S	and the second				
Parent survey status:	· · · · ·					
Teacher survey status	: Next surv	ey				
Family Preferences a	and Goals	Updated:				
Preference	Rating	g Con	cerns			<u> </u>
Behavior Therapy	Interm	ediate Acce	ptability			
Medication	Strong	None				
Goal of Improving:	Priori	ty Prog	ress Towar	d Goals as o	f	
School Performance	Mediu	m <mark>Abou</mark>	t the Same			
Relationships	Relationships Low		t the Same			
Behavior	Mediu	m <mark>Abol</mark>	t the Same			
Personal Goal: stop p			n. fingers, toys,	clothes, etc.,ca	aring or focusir	ng on completing
thinks he doesn't want to						
ADHD Assessment S	cales (Va	nderbilts)	Received (b	y responde	ent):	
Parent/Guardian Tea	cher:					
Survey		Initial	Follow-up	Follow-up	Follow-up	Follow-up
On medication?		Unsure	Yes	Yes	Yes	Yes
Inattentive Symptoms		7/9	5/9	1/9	3/9	0/9
Hyperactive Symptoms		1/9	2/9	1/9	1/9	0/9
Performance - Academic		3/3	2/3	2/3	2/3	3/3
Performance - Classroon	n	2/5	1/5	0/5	1/5	1/5
Subject/Class		second	second	second	second	second
		grade	grade	grade	grade	grade
Behavior Screen		0/10	-	~	-	-
Anxiety/Depression Scre	en	0/7	-	-	-	-
Side Effects		N/A	Present			Present

#### Figure 2. Copyright, 2014. The Children Hospital of Philadelphia. Reprinted with permission.

Notes: This screenshot of the ADHD Care Assistant indicates the findings from the parent-reported ADHD Preferences and Goals Instrument and teacher-reported Vanderbilt teacher ratings scales for a second grade student. The figure indicates the strength of family preferences for behavior therapy and medication as treatments for ADHD; the degree to which child school performance, social relationships, and behavior are goals for treatment; and the extent of progress in meeting goals. The figure also depicts the results of initial and follow-up Vanderbilt teacher rating scales. The findings indicate the number of inattention, hyperactivity, disruptive behavior disorder, and anxiety/depression symptoms endorsed and the number of impairments present in academic performance and classroom behavior. As indicated, the child was placed on medication after the initial assessment. A reduction in inattention symptoms was noted over the course of treatment, although there was little reduction in impairment. The Care Assistant indicates that there were side effects to medication that ought to be reviewed by the clinician. Color coding was used to facilitate rapid interpretation by the clinician: Red indicates a problem, yellow indicates a potential concern, and green indicates a lack of concern.

priorities, and they also expressed interest in reducing the child's tendency to put things in mouth and improving the completion of school work. The text that appears alongside the personal goal is entered directly by the parent and not edited. The initial Vanderbilt teacher rating scale revealed clinically elevated inattention symptoms (seven of the nine symptoms endorsed) and concerns about academic performance and classroom behavior. The child demonstrated only one symptom of hyperactivity impulsivity and no evidence of disruptive behavior disorders or internalizing disorders. Recognizing the need for providers to rapidly review information in fast-paced office practice, color coding in the clinician portal was used to facilitate interpretation: red indicates a problem, yellow indicates a potential concern, and green indicates a lack of concern.

A strength of the ADHD Care Assistant is its ability to track progress over time in one central location. The screenshot in this figure shows the results of Vanderbilt follow-up teacher rating scales. The child was placed on medication after the initial assessment. Over four follow-up assessments, the number of inattention symptoms declined from 7 to 0 during the course of medication treatment. Classroom behavior problems declined from 2 of 5 to 1 of 5, but academic difficulties remained unchanged, highlighting a target for future revisions to the plan of care.

#### Feasibility study

A study was conducted to examine the feasibility of using the ADHD Care Assistant. In addition, we investigated factors related to use of this tool in primary care practice.

#### Participants

The feasibility study was conducted in the primary care network operated by The Children's Hospital of Philadelphia. The network consists of 27 practices (235 PCPs) located in Philadelphia and surrounding counties. The number of providers in these practices ranged from 2 to 31 (median = 7). Providers were invited to participate in an educational intervention study designed to improve their use of evidence-based practices for managing ADHD. Nineteen (19) practices agreed to participate in this study and 105 providers in these practices offered consent. The number of study participants across these practices ranged from 1 to 14 (median = 5). Although the ADHD Care Assistant was offered to providers across the entire CHOP network, approval to extract data for the purposes of research was obtained only for the practices and providers who participated in this intervention study.

The study reflects Care Assistant usage for patients between 5 and 12 years of age. These patients were served in practices situated in urban and suburban communities across a broad range of socioeconomic levels. The percent of patients eligible for Medicaid across the practices ranged from 7 to 71%. In addition, advisory groups including 15 PCPs, 4 parents, and 5 teachers provided input to the project team about challenges in using the Care Assistant as well as strategies to address these problems. Parents and teachers were selected for these groups by the research team based on perceptions of their likely willingness and ability to contribute to the development process. The input of PCPs was elicited in the context of a quality improvement project designed to improve the use of evidence-based practices for managing ADHD in primary care settings. The study was approved by the Institutional Review Board of The Children's Hospital of Philadelphia.

#### Metrics and data analytic methods

Usage of the Care Assistant was examined during the period from 1 December 2014 to 31 July 2015. Teacher data were evaluated only for the six-month period until 31 May because schools in the region started to close for the academic year in early June.

Feasibility information was obtained by extracting data from the EHR for study providers and their patients with ADHD for whom the ADHD Care Assistant had been activated. Among children for whom the Care Assistant was activated, the percentage of children for whom parents and teachers completed the surveys was computed. Also, among children for whom the initial surveys were completed, the percentage of children for whom follow-up surveys were also completed was computed. Given that there are no established benchmarks for determining high vs. low patient Medicaid status per practice and high vs. low rates of provider participation per practice, a median split was used. Also, given that there are no benchmarks for determining extent of Care Assistant use, levels were identified that included a relatively equal number of providers. Variations in Care Assistant usage and rates of survey completion were analyzed as a function of practice setting (urban and/or suburban), Medicaid status (based on median split: <25% vs. ≥25%), and rate of provider participation in the study per practice (based on median split: >80% provider participation per practice vs. ≤80% participation). The proportion of providers using the Care Assistant and the proportion of parent and teacher surveys completed were calculated for each practice characteristic stratum. Variations in Care Assistant usage were differentiated into no usage, low usage (1-4 uses), and high usage (5 or more uses); the frequency of providers per level of usage was 35, 36, and 34, respectively. P-values were estimated using separate bivariate ordinal logistic regression models for each characteristic that accounted for the clustering of observations within practices. In addition, we computed the change in Vanderbilt raw scores for the 18 ADHD symptom items (scores ranging from 0 to 54) for all children with at least two completed surveys during the study period. The change score was computed as the difference between the first and last completed surveys.

#### Results

Demographic characteristics of the pediatric practices and providers are indicated in Table 1. Most of the providers worked in suburban practices. Although only 6 of the 19 practices had a Medicaid rate greater than or equal to 25%, the practices serving a relatively high Medicaid

 Practices
 Providers

 Practice setting
 3 (15.8%)
 32 (30.5%)

 Suburban
 16 (94.2%)
 73 (60.5%)

Table 1. Number and percentage of practices and providers as a function of practice setting, Medicaid status, and practice participation in the study.

Tractice setting		
Urban	3 (15.8%)	32 (30.5%)
Suburban	16 (84.2%)	73 (69.5%)
Medicaid status		
>25% Medicaid	6 (31.5%)	54 (51.4%)
25% Medicaid	13 (63.4%)	51 (48.6%)
Practice participation in study		
>80% providers in study	6 (31.6%)	52 (49.5%)
<80% providers in study	13 (68.4%)	53 (50.5%)

population generally were large and accounted for about half of the providers. One-half of the practices had a study participation rate among providers of at least 75%.

#### Practice and provider variation in use

Among 105 participating primary care clinicians, 70 (67%) activated the Care Assistant for at least one patient during the eight-month project period. Across practices, the percent of providers within the practices who used the system ranged from 0 to 100% (median 75%). At seven practices, 100% of participating providers used the system. The number of surveys sent out by individual providers who activated the Care Assistant ranged from 1 to 54. Across practices, 32% of providers activated Care Assistant for at least 5 patients, and 15% activated it for 10 or more patients. Of note, providers vary widely in the number of children with ADHD under their care.

#### Parent survey completion

Between 1 December 2014 and 31 July 2015, a total of 507 initial parent surveys were sent out through the ADHD Care Assistant. The initial surveys included the ADHD Preferences and Goal Instrument and Vanderbilt initial parent rating scale. Of these surveys, 279 (55%) were completed. A total of 160 patients also had at least one follow-up survey completed in this period (57% of those completing the initial survey). Of parents who completed one follow-up survey, 107 (67%) completed at least two. The maximum number of parent follow-up surveys completed was seven.

#### **Teacher survey completion**

Between 1 December 2014 and 31 May 2015, a total of 171 teacher surveys were initiated; these surveys included the Vanderbilt initial teacher rating scale. Of these, 165 (96%) surveys were completed. The number completed (165) reflects 33% of cases for which the Care Assistant was initiated by the PCP (507). Out of the 279 children with an initial parent Vanderbilt completed, 140 (50%) also had an initial teacher Vanderbilt completed during the study period. Of children with an initial teacher Vanderbilt, 82 (50%) had at least one follow-up Vanderbilt teacher scale. Of those with any follow-up surveys, 48 (59%) had at least two, and the maximum number was six follow-up surveys.

#### Factors influencing care assistant usage and rating scale completion

Rates of Care Assistant usage as a function of practice setting (urban vs. suburban), Medicaid status, and practice participation in the study are indicated in Table 2. Care Assistant use was lower (p = .004) in practices serving a greater proportion of Medicaid patients ( $\ge 25\%$ ). Differences in Care Assistant use did not vary significantly as a function of practice setting, although there was a trend toward lower use in urban practices (p = .10). The association of Care Assistant usage with rate of practice participation in the study among providers was not significant. In general, rates of parent and teacher completion of rating scales did not vary as a function of the demographic factors examined. An exception to this rule was that

	No CA Use	Low CA Use	High CA Use	p value
Practice setting				
Urban	13 (40.6%)	16 (50.0%)	3 (9.4%)	.1
Suburban	22 (30.1%)	20 (27.4%)	31 (42.5%)	
Medicaid status				
>25% Medicaid	24 (44.4%)	24 (44.4%)	6 (11.2%)	.004
<25% Medicaid	11 (21.6%)	12 (23.5%)	28 (54.9%)	
Practice participation				
>80% providers	16 (30.8%)	19 (36.5%)	17 (32.7%)	.8
<80% providers	19 (35.8%)	17 (32.1%)	17 (32.1%)	

Table 2. Number and percentage of providers with varying levels of ADHD Care Assistant use as a function of practice setting, Medicaid status, and practice participation in study.

Notes: CA refers to the ADHD Care Assistant. Low use refers to 1-4; high use refers to >5. Practice Participation refers to practices that had >80% (or <80%) of providers in the practice participate in the study. *P*-values account for clustering by practice site.

there was a lower rate of parent rating scale completion in urban (48%) as compared to suburban (56%) practices (p = .006).

#### Vanderbilt score changes

Changes in parent and teacher Vanderbilt raw scores for the 18 ADHD symptom items (range from 0 to 54) were calculated for all children with at least two complete surveys between December and July. We computed change scores by subtracting raw scores for the last completed survey from scores for the first completed survey. We were able to calculate change scores for 57% of parents completing the initial assessment, and 50% of teachers completing the initial assessment. Overall, parent scores improved by an average of 5.6 points, and 68% of children with at least two parent surveys had an improvement in symptoms. Teacher scores improved by an average of 5.5 points and 59% of children with at least two teacher surveys improved.

#### Challenges in using the ADHD Care Assistant

A number of barriers were identified from advisory committee meetings with PCPs, parents, and teachers that may have impeded use of the ADHD Care Assistant. First, providers identified workflow issues in the operationalization of the portal. Parents were required to sign a HIPAA consent form annually, which was scanned into the EHR prior to activating the portal. Providers reported that this process sometimes interrupted their office workflow and added time to their clinic visits. In addition, providers in some offices reported that they currently use nursing and support staff to handle paper rating scales but have no procedure for handling electronic forms. Introducing an electronic portal necessitated a change in office workflow procedures and potentially shifted work from support staff to clinicians. Second, providers reported (and quantitative results confirmed) that parents were inconsistent in responding to sent emails requesting that surveys be completed. The Care Assistant was designed to have providers input parent email addresses, and the system would then email parents with rating scale requests at periodic intervals. However, the rate of parental completion of rating scale requests was modest (55%), and a number of parents anecdotally

#### 12 🔄 T. J. POWER ET AL.

reported not receiving such emails from the portal to complete rating scales. Third, teacher participation in completing rating scales was dependent on parents providing written instructions and a signed FERPA consent form to teachers. If parents did not provide the forms to teachers, teachers would not have the instructions and codes needed to receive the online survey and complete the rating scales using the Care Assistant. In addition, the portal only permitted responses from one teacher per child, and some children in the study age group had multiple teachers. As a result of these barriers, only 33% of patients for whom Care Assistant was activated had a teacher-completed rating scale. Fourth, some providers stated that they did not use rating scales or preferred rating scales other than the Vanderbilt. Finally, pediatric providers and teachers reported that some teachers and school districts have been wary of sharing information electronically and were not willing to complete electronic rating scales. This issue reflected multiple concerns, including questions about the protection of student privacy, limits on ability of school professionals to orchestrate the collection and reporting of data, failure to account for rating scale data that had already been collected in the school, and questions about how the information reported by the teacher would be used by the PCP.

#### Potential strategies for overcoming challenges to use of the ADHD Care Assistant

Advisory group members offered several suggestions about how to overcome challenges in using the ADHD Care Assistant. First, to improve workflow concerns, it was recommended that office or nursing staff assist in obtaining signed HIPAA consent forms when required. This could be accomplished at the time of a visit or prior to visits by mailing or faxing the forms to parents and asking them to return them to the office. Second, to ensure that parents receive email notification to complete rating scales and to encourage completion once the notification is received, it was recommended that pediatric providers activate the portal during a clinic visit with a parent and then ask the parents to check their email on their smart phones to ensure they received the notification prior to departing the office. Third, to improve rates of parent completion, parents suggested that the length of the initial survey, which included the Preferences and Goal Instrument and Vanderbilt scale, be shortened. Fourth, to improve teacher completion of rating scales, it was suggested that the teacher instruction and consent forms be mailed directly to the child's teacher along with an introductory letter. This procedure could be done in addition to providing parents with the forms and asking them to provide these to their child's teacher. In addition, when there are multiple teachers, although it may be logistically challenging, it was suggested that a single teacher be asked to complete the scale after conferring with other teachers. Fifth, to encourage provider use of the electronic portal and the embedded rating scales, it was recommended that instruction on the rationale, use, and scoring of the Vanderbilt Scales be offered to providers. We did provide this as an online educational webinar (Learning Link) with the availability of continuing education credits for those who completed the training. In addition, scoring of the rating scales was automated through the Care Assistant, and the results were offered to providers through the portal as color coded ('red' elevated, 'yellow' borderline, and 'green' normal ranges) to facilitate quick and easy interpretation. Finally, to overcome teacher and school reluctance to provide electronic completion of rating scales, educators recommended that discussions ensue with county-based or state-based superintendents, who provide oversight and services to all school districts within a county, region, or state.

#### Discussion

Our project team was successful in creating an electronic system to collect information from parents and teachers that is useful in making diagnostic decisions about ADHD, engaging parents in shared decision-making, and monitoring treatment outcomes. A unique feature of the system is that it was directly linked to the EHR so that providers could have rapid access to completed surveys. In addition, the results of parent and teacher rating scales were color coded so that the clinician could easily interpret the information and provide meaningful feedback to families. At several practices, use of the Care Assistant was common practice and the general norm for providers in the office. Providers reported that the system's flexibility in obtaining outcome data at variable intervals was a useful feature.

Although the American Academy of Pediatrics has recommended that pediatric clinicians should obtain information from parents and schools in the management of ADHD (AAP, 2011), providers vary in their willingness and ability to do so (Guevara et al., 2005). Our study reflecting results from 19 diverse practices affiliated with The Children's Hospital of Philadelphia demonstrated that two-thirds of providers activated an electronic tool to obtain ADHD rating scales from parents and teachers. These results were heterogeneous by practice, suggesting that practice characteristics influenced the perceived utility of the tool.

Care Assistant usage was found to vary as a function of patient's Medicaid status. Overall, the rate of usage was lower among providers serving a relatively high percentage ( $\geq$ 25%) of Medicaid patients. In addition, the rate of parent survey completion was lower for urban as compared to suburban practices. Additional research is needed to identify factors contributing to these disparities across practices, including provider characteristics (e.g. provider concerns about parental resources to use electronic systems), practice characteristics (e.g. administrative resources to support changes in practice workflow to support electronic systems), and family characteristics (e.g. parental preferences for print vs. electronic forms; parent accessibility to the Internet; and/or parental health literacy).

As illustrated, the Care Assistant can be used to examine changes in ADHD symptom ratings over the course of a specified period. In this feasibility study, the change in parent and teacher ratings was modest in size. Change was reflected even though many patients had already been placed on medication before enrollment in Care Assistant, the type of treatment received by patients (i.e. medication status and/or involvement in behavior therapy) varied substantially, and the length of the interval between first and last survey completion varied markedly. Although the generalizability of the actual change scores identified in this study is questionable, these findings illustrate the feasibility of tracking symptoms (and changes in symptoms) over time using the Care Assistant. An analysis of factors that contribute to changes in symptom ratings from first to last assessments is an important area for future investigation.

Advisory groups of PCPs, parents, and teachers identified numerous challenges and proposed solutions for improving implementation of the Care Assistant. The recommendations included modifications to ADHD Care Assistant, system changes in primary care practices to improve workflow, provider education to parents about how to collaborate effectively with school professionals, and broad education to local school districts as well as county-based school systems. It is clear that strategies to improve implementation of an electronic system like ADHD Care Assistant must include more than improvements to the technology itself; professional education and changes within and across the primary care and school systems are required to improve implementation and care coordination (Power et al., 2013).

#### Limitations of the feasibility study

The feasibility study described in this article had several limitations. First, findings are reported only for the subset of practices and providers who elected to participate in an educational intervention study to learn about the management of ADHD. These providers likely had a relatively strong interest in managing or improving their care of ADHD and behavioral health problems in primary care. As a result, the generalizability of the findings to providers with a lower investment in managing behavioral health problems is uncertain. Second, the study was conducted in practices affiliated with a large children's hospital in the northeast section of the country. The barriers and resources for conducting a project like this may differ in other regions of the country and in practices that are not affiliated with an academically affiliated hospital. Third, the findings are specific to the electronic system used in this project, which differs from electronic systems that have been developed in other institutions. For example, unique features of the ADHD Care Assistant are that it is linked to the EHR and collects assessment information that is useful for shared decision-making. However, a limitation of this system is that it can accommodate only one teacher rating scale at a time. In addition, the workflow of the ADHD Care Assistant requires parents to collaborate with the teacher in order for the teacher to activate the system. Parents vary enormously in their willingness and ability to collaborate effectively with teachers, which is often influenced by cultural factors (Holloway & Kunesh, 2015). A potentially fruitful avenue for future investigation would be to examine strategies for actively supporting parents with school collaboration to promote use of electronic systems that facilitate management like the Care Assistant.

#### **Future directions**

The current version of ADHD Care Assistant fosters the use of evidence-based practices in managing ADHD, likely resulting in an improvement in guality of care. Nonetheless, there are limitations that need to be addressed in the future. First, the current version enables the findings obtained through the portal to be visible only to PCPs and only supports oneway communication from parents or teachers to providers. The Care Assistant is currently being revised to support bidirectional communication, including the potential electronic sharing of parent preferences and goals and child's progress with the teacher. Obtaining ongoing consent from families for the sharing of patient information with teachers is a difficulty that must be overcome to support this process. Our team's Parent Advisory Committee and Teacher Advisory Committees are working with us to address these challenges. Second, the existing version of Care Assistant is designed for children between the ages of 5 and 12 years. This version has noteworthy limitations for the management of adolescents with ADHD because it does not include a mechanism for obtaining ratings from multiple teachers, does not address sufficiently mental health issues that are common among teens including depression and substance abuse, does not include a method for obtaining adolescent self-ratings, and does not address potential adverse effects of medication use in adolescents, especially risk for abuse and diversion of medication for illicit or inappropriate purposes (Hoeveler & Power, 2015). Our team is currently conducting research to identify the unique practice needs of providers addressing the concerns of adolescents with ADHD so that electronic systems can be adapted for this population. Finally, it is likely that the needs of many patients with ADHD cannot be addressed sufficiently with electronic practice supports and decision tools. For example, some families, in particular those coping with high levels of stress or those with fewer resources, may need additional support and guidance. Based upon research on the use of a collaborative care model for the treatment of depression (Gilbody, Bower, Fletcher, Richards, & Sutton, 2006), our team is examining the role of a care manager based in primary care practice to determine whether the involvement of this individual to coordinate care and provide education improves intervention effects for children with ADHD (Guevara et al., 2009). We are also investigating the conditions under which such a model may be needed so that the resources of a care manager can be directed to families most likely to benefit from the supports.

#### Conclusions

As this article illustrates, electronic systems for assessing ADHD and monitoring treatment outcomes appear promising for increasing parent and teacher engagement in care, facilitating communication with pediatric providers, and identifying areas where treatment is effective or additional strategies are needed. As such, it is likely to support ongoing treatment decision-making focused on ameliorating symptoms and helping families reach their goals. Research and quality improvement activities are needed to improve these systems so that rates of provider usage are higher, disparities in system usage and survey completion are reduced or eliminated, rates of rating scale completion are higher, and parents and teachers can become more actively involved with PCPs and teachers in collaborative care.

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18 🔄 T. J. POWER ET AL.

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