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Use of an Online Clinical Process Support System as an Aid to Identification and Management of Developmental and Mental Health Problems

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Abstract

Purpose of review—To describe benefits and problems with screening and addressing developmental and behavioral problems in primary care and using an online clinical process support system as a solution.

Recent findings—Screening has been found to have various implementation barriers including time costs, accuracy, workflow and knowledge of tools. In addition, training of clinicians in dealing with identified issues is lacking. Patients disclose more to and prefer computerized screening. An online clinical process support system (CHADIS) shows promise in addressing these issues.

Summary—Use of a comprehensive panel of online pre-visit screens; linked decision support to provide moment-of-care training; and post-visit activities and resources for patient-specific education, monitoring and care coordination is an efficient way to make the entire process of screening and follow up care feasible in primary care. CHADIS fulfills these requirements and provides Maintenance of Certification credit to physicians as well as added income for screening efforts.

Keywords

developmental screening; pediatrics; mental health screening; clinical decision support; care coordination; Maintenance of Certification

Introduction

While electronic health records (EHR) assist in documentation of care and facilitate prescription writing they do not play much role in addressing the clinical issues related to identification and management of developmental and behavioral problems. CHADIS (Child

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Health and Development Interactive System) is an online system that was specifically developed to assist in the identification and management of pediatric developmental and behavioral issues beginning with early identification and management in primary care. It also supports referral to developmental and mental health specialty care when appropriate. System use begins prior to the face-to-face clinical encounter and employs pre-visit patient-generated data to trigger individualized decision supports for use by clinicians during the visit, provides individualized health education and offers targeted monitoring between visits. If physicians choose to use the decision supports they become eligible for specialty board Maintenance of Certification (MOC) quality improvement credits. Since the system provides support for the entire clinical process it is called a “clinical process support system”. While some freestanding online systems (PatientTools, ASSESSMD, PedsTest, BabyNoggin) and some EHRs offer a limited number of screening tools, CHADIS is the only comprehensive “clinical process support system” with these other features.

Two lead commentaries in the New England Journal of Medicine, highlight the value of pre-visit and also post-visit structured patient generated data, of which developmental and behavioral screening is a subset, called “patient reported outcomes” or “PRO”. “Patient-Reported Outcomes – Harnessing Patients' Voices to Improve Clinical Care[1]” reviewed randomized trials of “PRO” for serious medical conditions such as cancer and showed a reduction in ED visits and even prolonged survival. The second article, “Making Patients and Doctors Happier – The Potential of Patient-Reported Outcomes”[2] summarized interviews of doctors using “PRO.” This commentary envisioned great impact of patient generated data on the whole health care system, concluding that “PROs could help sustain the size and spirit of the physician workforce, providing a much-needed path to a stronger health care system.” The main limitation to adoption noted was lack of “..availability of standardized PRO platforms that could accompany or easily be plugged into the EHR.” The system described below is an example of such a PRO platform currently used in pediatric practice addressing the issues of developmental and behavioral screening.

The need for screening

It is estimated that 10.6-21.5% of children have developmental or behavioral disorders[3], overall the most common chronic conditions in children. 40-50% of well child visits reveal clinically significant behavioral, psychosocial or developmental issues[4]. 75% of children with psychiatric disorders are first seen in primary care[5]. As a result of this need the American Academy of Pediatrics (2010)[6] recommended routine mental health screening.

Screening for developmental and behavior problems is valuable for many reasons. Using valid screens actually take less time than “reassurance” of parents (who know the child best and are often correct in their worries). The screens become data for referral and a baseline to track progress. The primary care provider (PCP) may be the only professional involved with a child before school-age in a position to identify problems. Using a formal screen for mental health disorders is critical since various studies have found that mental health disorders are only detected in 14%[7,8, 9] - 20% [10] of those with disorders by PCPs during routine care. Even when a child is well known in a practice, only ½ with mental health disorders are identified[11]. 75% of parents of children with a mental health disorder

did not bring it up during the primary care visit, sometimes due to lack of recognition themselves but also due to perceived unacceptability of asking questions about emotional functioning (sometimes cultural), shame, stigma or lack of confidence that a PCP could help[12]. Patients and even some PCPs have skepticism about the effectiveness of interventions and uncertainty about appropriate steps after a positive screen and therefore do not bring it up [12].

As a result of these failings and the importance of intervening as early as possible[13, 14], the AAP[6] recommended social-emotional, mental health and psychosocial function screening annually from age 5 to 18 in addition to development and autism screening[15] at younger ages. It is suggested that a screen specific to social-emotional functioning also be conducted if a general screen or autism screen is abnormal. For adolescents, substance abuse screening is recommended annually. In addition trauma surveillance is called for annually and family screens, such as maternal depression and intimate partner violence, should be done early in the child's life.

The Clinical Challenge for Primary Care

Reviewing the scope of these recommendations for screening, not even considering the extensive list of topics to be discussed as advised by Bright Futures, it is not surprising that PCPs during visits are “Drowning in a Sea of Advice” [16]. Knowing which tools to select, for which ages and types of problems, acquiring, organizing, distributing, collecting, scoring, reviewing, and filing them in charts are costly in person-power and stress office workflow when done with paper tools. In addition, clinicians may not have time, skills or resources to interpret results, talk with families compassionately and effectively, identify resources to help with problems, provide patient-specific educational materials, refer and assure follow up with families. Any change in how care is delivered also requires change in patient expectations and office workflow that require systematic implementation. Cultural, language and stigma issues may also affect screening programs.

A Clinical Process Support System Solution

CHADIS is a web-based system designed to assist in the provision of evidence-based individualized care to optimize health and well-being while educating both patients and clinicians. CHADIS comprises a “clinical process support system” since it assists in several facets of the clinical process:

1. **Prior to the visit**, patients and/or parents complete questionnaires that are automatically assigned appropriately for the type of the planned visit and the patient's age. These online tools collect information on the patient's priorities and strengths as well as issues and symptoms and include validated screens, outcome measures and diagnostic assessments as well as simple data collection.
2. **During the visit**, CHADIS provides decision support to the clinician specific to the patient based on the pre-visit data ranging from scored results and bulleted guidelines to graphic presentation of results to assist in shared decision-making with the patient.

3. **After the visit**, CHADIS offers targeted education and engagement for both patients/families and clinicians. The patient is provided tailored feedback in an individual webpage MemoryBook Care Portal, accessed through the same site as the pre-visit questionnaires. For clinicians, CHADIS offers educational opportunities such as e-chapters, videos, policy guidelines and links to the National Library of Medicine and case discussions as well as the option to earn required Board recertification credits via webcast feedback sessions. Care coordination functionality also allows for online consent, secure transmission of notes and results and confirmation of kept appointments.

The CHADIS system addresses almost all issues about screening as described below. As a result of the advantages of electronic systems, the President's "New Freedom Commission on Mental Health" recommends using "technology to access mental health care and information… in an integrated electronic health record and personal information system." [17]

Saving Time and Addressing Workflow Issues

One solution to the problem of time needed for conducting evidence-based comprehensive care in short health supervision visits is to have parents and teens complete validated tools pre-visit outside of visit time, either at home or in the waiting room. This gives the parent or teen time to consider and prioritize their concerns and shows that the PCP cares about these topics. When screens are completed online the work for staff is reduced as the correct tools for age and problem were assigned once at the time the system set up for an office and are scored automatically and accurately. Either staff or the PCP can simply electronically copy then paste the results into a field of their EHR (if CHADIS is not yet integrated), create and attach a pdf, print to scan the results or print for a document for paper charts. Offices do not want the front desk to have to decide which questionnaire to give to which parent/teen based on age of the child or to have to adjust for prematurity as needed for developmental screening. Therefore a program focused on behavior and development screening will be easier to adopt if it contains screens for all recommended areas of pediatric care. The more comprehensive pre-screen system actually creates greater efficiencies at the time of the visit than a more narrowly focused system. When the PCP is freed up from having to ask for all the recommended safety, guidance and other questions there is more visit time available to respond to behavioral and developmental concerns. The PCP can see the report of the child's problems and strengths before starting the visit allowing him/her to better prioritize with the family how to use their visit time to manage problems rather than asking myriad questions or discovering crucial issues as they end the visit with the proverbial "doorknob question." If elements of AAP recommended advice such as safety are omitted during the time-limited visit when other issues are prioritized, the PCP can feel reassured that individualized safety reminders will be made available on the secure web page (MemoryBook Care Portal) or as a printable handout for the family based on pre-visit parent data indicating the particular safety recommendation is not yet being addressed.

In a recent article cited earlier, interviews of doctors who were using pre-visit and monitoring tools (not CHADIS) revealed benefits to workflow and job satisfaction such as "…saved about 10 minutes on each annual physical" and "..enabled her to 'be a doctor

again'… no longer forced to wade through verbal checklists during visits. Instead, she examined and communicated, focusing on the issues[2]." This commentary concluded that these pre-visit questionnaires were improving physician satisfaction in general and preventing burnout[2].

Assuring Accuracy and Reliability of Responses

Computerized questionnaires have additional advantages. 45% of adults felt better able to formulate questions at the time of the face-to-face encounter after completing online pre-visit screens[18]. It has also been found that more confidential data is uncovered by data collection by computer than by an interviewer including issues of: suicidal intent, alcohol use [19], high risk sexual behaviors[20, 21, 22], and drug use[23]. Our group compared preferences of low income and middle income parents completing the M-CHAT autism screen on computers, tablets and phone vs. paper. Both groups most preferred tablets but the low-income group in addition least preferred paper [24]. Scoring is always accurate when done by the computer, while even simple questionnaires are often not scored at all in practice[25] violating a requirement for reimbursement, as well as compromising their clinical accuracy and utility. Patients always have the option of providing misinformation based on inaccurate observations or insight, not choosing to disclose, or declining to answer at all, but these are all possible in the case of in-person interviews as well. Validated tools have taken these factors into account in assessing sensitivity and specificity for a conclusion unlike interviews, however.

Addressing Language Barriers—Many offices are caring for patients who speak a variety of languages. All questionnaires in CHADIS are provided in Spanish as well as English and most in French. Patients click a link at the top of any view to see items in another language with results appearing for the clinician in English. Other languages can be accommodated. This allows patients to answer in their preferred language but clinicians to be able to accurately determine the meaning of the endorsed items. CHADIS also has handouts in Spanish as well as English adjusted for a literacy level below 6th grade, in general. For low literacy patients, CHADIS can present items on a tablet in kiosk mode responding to the touch screen and a few questionnaires are set up to read the items aloud in English or Spanish. Alternatively, an assistant could read items to the patient and enter responses just as they would do for paper tools but with the other advantages as noted.

Adherence to pre-visit questionnaires by patients—Adherence to completing screens is a potential issue in any screening effort. Using CHADIS, when appointments are made parents are asked to complete questionnaires from home on the CHADIS website using an office-specific invitation code to register. The invitation code is the same regardless of the child's age or visit type making instructions easy for the front desk staff. Once registered the parent or teen selects the type of appointment from a list for that office that then presents the preselected set of questionnaires for their completion. An email or text reminder is sent two weeks before any age-related Health Supervision Visit (HSV) with up to two additional reminders if the parent or teen does not complete the questionnaires during the interval. Reminders to complete questionnaires between visits can also be set up for a given patient, a panel of patients, or the entire practice. If the parent or teen appears in the

waiting room without completing the questionnaires they are usually handed an inexpensive tablet that is locked down to the CHADIS website or they can use a laptop or their own smartphone to complete the questionnaires.

Adherence rates vary by patient demographics but more by the organization and leadership of the practice for any screening effort. CHADIS offers implementation support via live interactive webinars or by phone. Several Quality Improvement programs for screening using CHADIS for data collection are available for Maintenance of Certification credit. These use the Plan-Do-Study-Act paradigm of cycles of incremental improvement and feedback including optimizing patient adherence to completing requested screens. An independent evaluation published in Pediatrics of an early version of CHADIS showed a "high degree of parent …and doctor satisfaction[26]." Patient feedback has included positive comments about: comprehensive and scientific care as well as about the fact that their visit priorities were addressed.

Knowledge, Access to and Availability of Diagnostic Tools—Another barrier to screening is PCP lack of knowledge or tools to further define the child's issues in the case of a positive screen, either to sort out the common false positives or to have enough specifics to diagnose or accurately refer true positives. By being able to identify patients and collect data using the online system we were able to do the research needed to create and validate online parent-report diagnostic tools using DSM-PC[27] and subsequently DSM-5 [28,29] criteria that are more accurate than the standard Child Behavior CheckList[30] in detecting disorders and additionally show specific diagnostic criteria as needed for coding and billing. Similar research allowed creation of the only parent-report tool yielding potential Diagnostic Classification 0-3R[31,32] mental health diagnoses for 1-6 year olds, an important age gap for early detection. All of the above tools as well as all tools in the system by other authors can be "chained" to be delivered online automatically at the same pre-visit session in the case of a positive screen or assigned individually by the clinician for later completion. The availability of these tools and functionality particularly facilitates compliance with the AAP guidelines for care of ADHD that includes seeking and managing conditions comorbid with ADHD [33], a major gap in care by PCPs[34].

Features

1) Pre-Visit Features

Patient-completed tools: CHADIS assists in implementation of all AAP, Bright Futures[35] and Medicaid guidelines for preventive screening and education for child health supervision and problem visits. Parents and/or teens complete computerized questionnaires about the child's health, behavior, development, health risks, family risks and protective factors, and child strengths. CHADIS tools can be completed online at home or in the health care office in a language of the patient's choice using a computer, a tablet in kiosk mode via touch screen, via smartphone or on a regular phone that reads select tools aloud.

Clinicians select from over 400 questionnaires in CHADIS to set up a profile of tools to be automatically assigned depending on the child's age and the type of visit e.g. health supervision, initial behavior visit, asthma follow up visit, etc. These questionnaires can be

selected to cover all the routine data collection normally required for child HSV including nutrition, sleep, toileting, exercise, safety, Medicaid required state specific EPSDT health risks and family/social factor tools. A broad array of the highest quality tools for all areas of pediatrics where validated tools are available have been selected. In addition, unvalidated data collection tools are also included to assist the clinician with documentation. There are currently 49 validated child mental, emotional and behavioral health screening tools for parents and an additional 24 for teen self-report included. Forty-six other tools would be considered diagnostic (rather than screening) mental health tools that may be used in pediatrics. The system delivers 37 validated developmental and autism screening and diagnostic tools and 19 validated family/environment tools. In addition, some unscored data gathering tools are available to facilitate assessments such as a developmental milestones review as well as many tools for general pediatrics. Adolescents can complete self-report tools and all results are available to clinicians but not to parents or patients.

One issue with screening is that concern is raised by a positive screen but without a diagnosis or current status being determined. One solution is to automatically “chain” from select screening results to more in-depth tools at the same sitting. For example, a questionnaire about priorities for a check-up visit has a question listing the Children with Special Health Care Needs chronic conditions. When parents indicate that the child has asthma, a validated questionnaire about asthma severity (Pediatric Communication and Control Instrument[36] or PACCI) is triggered for completion. In a study[37] of over 36,000 HSVs and asthma-specific visits we found that 78% of children with persistent asthma symptoms indicating a need to intensify treatment would likely have been missed by the typical informal asthma symptom assessment during HSVs without use of a standard tool. Use of scheduled PACCI monitoring questionnaires between visits is currently being tested as a way to further optimize management and asthma control. Knowing from a pre-visit assessment that a child's asthma is out of control allows for planning a longer visit.

2) Within Visit Features—Clinician lack of knowledge or skills for managing development or behavioral issues is a common barrier to screening[15] that is addressed by this online system.

Assistance with choice of tools: Clinicians can confer with CHADIS staff in choosing tools to use for different ages, visit types and conditions. Suggested templates of tools by age and visit type are available. Tools are listed and available to preview from a clinician dashboard with details about the length, age range, time for completion, scoring, past studies, etc. Additional tools, in any format, scored or simple data collection, can be entered by request including for specific research projects. Agreements with a number of publishing houses have been achieved for some proprietary tools.

Scoring and interpreting results: Computerization allows for all questionnaires to be instantly scored. All tools, scored or not, have results presented to the clinician in a word and numerical summary form, often with cut score embedded in the result. This obviates staff training and avoids errors and time for scoring. A summary table presents these results with positive results further highlighted with 1 − 3 star alerts of potential clinical severity for that

patient. This scoring and interpretation satisfies the requirements to bill insurance for the use of a screen.

Decision support for clinicians: Scored results of questionnaires appear in CHADIS's electronic worksheet where suggested diagnoses have links to information for the clinician, in the form of bulleted “eChapters” with definitions, possible trigger questions to ask, differential diagnosis, and management suggestions. Tools for the clinician to complete during the visit, such as more problem-specific questionnaires (e.g., CRAFFT[38]) or standardized interviews (e.g., Diagnostic Infant and Preschool Assessment[39]) are also linked for ease of access. One example of decision support is facilitation of a structured follow-up interview for positive autism screens (M-CHAT Follow Up Interview[40]) that is considered required by the tool's authors and lowers the over-referral rate of initially positive screens by 90%[40]. Conducting this interview required a follow-up phone call by a trained individual in initial studies. We have shown that prompts presented in CHADIS specific to the failed items allowed PCPs to very efficiently complete the required interview questions during the routine check-up visit, and predicted autism diagnoses as well as an interview by a trained individual at an autism center (Kappa=0.66)[41].

Assistance with “Shared Decision Making”: “Shared decision making” is a concept introduced in the landmark Institute of Medicine (IOM) report[42] as one of the fundamental approaches to improving the quality of U.S. health care and noted in an editorial as “the pinnacle of patient centered care[43].” Additionally, the IOM recommended review of goal setting as an important part of shared decision making. The AAP guidelines for ADHD care include goal setting and monitoring as important components[34], yet tools to assist in this task are lacking. We surveyed 441 parents prior to ADHD visits regarding their goals for care and developed a questionnaire with items representing 17 distinct goals with further delineation of subgoals[44]. Use of a goals questionnaire prior to the visit allows for tracking of goals and suggests targeted follow-up education related to the specific goal. In addition to pre-visit data collection aimed at helping patients take a role in setting the agenda for the visit, CHADIS provides some graphical representations of the data to enhance doctor-patient communication and patient engagement during the visit. For example, when the standard Vanderbilt ADHD ratings [45,46] are completed by parents and teachers (via a link sent from CHADIS initiated by office or parent), the results are displayed in a graphical color-coded form summarizing results from all raters over time. Shared decision making is also facilitated for asthma by a similar graphic of asthma severity level as well as a “mountain range” depiction of scores over time and icons representing reported adherence and extra care needed (ED, urgent care visits or steroid bursts). Optional graphics are provided to complement the motivational interviewing “teleprompters” for clinicians for discussing complex issues such as parental depression, substance use or intimate partner violence. The graphic illustrates ambivalence for behavioral change incorporating the pros and cons for change from the pre-visit questionnaires. These approaches to communication are being vetted by doctors and parent raters of interview transcripts.

Assistance with guideline-based care and evidence-based interviewing skills

Patient Specific Template (PST): The PST is a condition-specific guideline-based outline for care that is pre-populated by the patient's questionnaire results. Clinicians are aided by hints, links to guideline tables, photos of medications (e.g. asthma medications) and graphic displays of results as well as teleprompters to guide the face-to-face interview. The teleprompter provides language and suggested wording specific to the parent's responses in the pre-visit questionnaire for a Motivational Interview [47] in a model that is now being used in an intervention trial aimed at addressing issues of family stress such as intimate partner violence. Teleprompters are also undergoing field trials as part of decision support for Problem-Solving Counseling for non-adherent asthma patients and addressing social determinants of health in the form of family stressors. In these cases, clinical decision supports are derived from individual responses to pre-visit questionnaire results, making a personalized intervention and simultaneous clinician training. Patients do not see the results of the questionnaires completed in CHADIS unless a summary is sent to the Care Portal when the PSTs are used. PSTs also result in some pre-populated condition-specific care plans for the family in their Care Portal such as an Asthma Treatment Plan or to help address parent-identified goals for care for their child's ADHD.

Resource listings: Clinicians submit their preferred local resources for entry in the resource database when first licensing CHADIS. This can include their own custom handouts making them easily assigned by a click to the Care Portal or to be compiled for printing. There are now listings for >20,000 local as well as national listings, many in Spanish as well as English, including health education videos and edutainment “games” such as Lungtropolis[48] for asthma. Additional resources can be added at any time to customize for location or language preferences. Reviewing these “handouts” is valuable education for clinicians as well as patients. The report for the visit documents the titles of assigned resources for future reference.

3) Post Visit Features

Patient Engagement: Patient education is an expected part of comprehensive care and required by standards such as Patient Centered Medical Home.

MemoryBook Care Portal: The CHADIS MemoryBook Care Portal presents alerts, notices and resources selected by the clinician or automatically assigned based on questionnaire results. Select pre-visit questionnaire results are transformed into an individualized keepsake record for the child in the MemoryBook page of the Care Portal. For example, items from pre-visit developmental screening appear as milestones with links to suggested educational activities appropriate for the child with that skill plus the option for the family to insert comments and pictures. This forms a built-in personalized developmental stimulation curriculum for the family. The goal of the MemoryBook is to entice repeated visits to the Care Portal so that parents will see the health alerts and resources. Parents and teens can get further value from the Care Portal by searching and saving resources listings for themselves from the database.

Patient Reminders: Reminders with links into their CHADIS home page are sent automatically to parents or teens by their choice of text, email or both at certain times: 2 weeks before the expected age for HS visits based on office protocol, at intervals set for individual patients e.g. for Vanderbilts[45,46] for ADHD follow up; Patient Health Questionnaire-9 (PHQ-9)[49] for depression monitoring; or when new resources are assigned to their Care Portal by questionnaire results or by the clinician. There are also reminders to access the Care Portal sent about patient goals elected by the parent to encourage positive parenting or to build strengths elected by the teen.

Monitoring Functionality: Use of Patient Reported Outcomes (PRO)[1, 2] has been shown to improve care, longevity, and patient and doctor satisfaction. Collecting data from patients between visits allows evidence-based monitoring of conditions without the need for a visit. Reminders with links into their CHADIS home page are sent automatically to parents or teens as noted above for monitoring. The data is instantly available to the clinician for review. In addition, data on the status of groups of patients e.g. asthmatics with persistent symptoms, low adherence or deteriorating control can be sent securely to clinicians at intervals by request or as part of research studies.

Care Coordination Functionality: Care coordination is required under programs such as Patient Centered Medical Home and Accountable Care Organizations as well as payment mechanisms such as the Merit-based Incentive Payment System. Functionality within CHADIS allows for online parent or teen consent, secure transmission of notes and results and confirmation of kept appointments by an outside specialist regardless of any EHR used. Specialists can provide feedback on kept/unkept appointments as well as make comments, closing the circle of communication for integrated care.

Quality Improvement Programs: While the clinician's goal is to optimize care for individual patients using evidence-based guidelines, mandates now exist for ongoing quality improvement (QI) for practices a whole. CHADIS integrates patient generated data with documentation of clinician decisions from pick lists and autotext to support QI efforts. Certification by the American Board of Pediatrics as a “portfolio sponsor” has allowed CHADIS's parent, The Center for Promotion of Child Development through Primary Care, to develop Maintenance of Certification-Part 4 (MOC-4) programs for QI. Such programs have already been completed by >300 doctors. These programs use the Plan-Do-Study-Act paradigm of cycles of incremental improvement and feedback to assess outcomes working with the office staff as a whole. Current MOC-4 QI programs with the potential for earning 25 Part 4 credits each include developmental screening, autism screening, ADHD, asthma, and family stress. The family stress program is also available for credit for Family Physicians. Data such as patient registries (positive screens or parents reporting various chronic conditions) for individual clinicians, offices or systems can be provided for other QI efforts.

Population Health Data Collection

CHADIS is in use in 48 states and 9 countries and has delivered over 5 million questionnaires with currently >1,540,000 patients enrolled. The de-identified data comes

largely from community pediatric practices forming a unique population health resource. Practices have written agreements for de-identified research. Access is available by agreement with CHADIS leadership.

For example, the Pediatric Symptom Checklist (PSC) [49] in its various forms has been completed 432,105 times already and the Strengths and Difficulties Questionnaires[50] 28,026 times. For example, the authors of the Pediatric Symptom Checklist (PSC) [49] (Drs. Jellinek and Murphy) asked for data from CHADIS when they wanted to update the PSC norms as needed to for it to continue to be recommended nationally. The result provided the desired national recommendation for the test and a publication in the journal Pediatrics [51]. This rapid access to data (over 100,000 de-identified patient results were pulled instantly) was at no cost to the authors and resulted in a much larger and more representative sample than had been obtained in all their prior studies.

Some other mental health screening tools used commonly in CHADIS include teen self administered tools, such as the PHQ-9[52] for teen depression (65,737 uses) and CRAFFT[38] for substance use screening (116,859 uses). The Vanderbilt[45] for ADHD were used 118,252 times by parents and CHADIS also links to teachers[46] and brings results back with 33,122 administrations already. Data (mostly Vanderbilt parent and teacher) from CHADIS related to ADHD is now being used by the Office of the National Coordinator (ONC) of Health IT to validate and refine new clinical quality measures for pediatric ADHD care.

Assistance with Meeting Regulatory Requirements—Clinicians and practice networks are have rapidly increasing requirements to document aspects of care and their patient population to meet requirements, qualify for added income (e.g, Patient Centered Medical Home) and/or avoid penalties (e.g, Merit-based Incentive Payment System; EPSDT). Not all this data is available from the EHR, particularly clinician actions and may be a costly request or manual process. Access to regular reports from a routinely used online system can satisfy these needs.

The Potential of Research Networks—The large dataset available from multiple sites using the same online system facilitates discoveries and large-scale research both through national level community samples and also through regional networks when additional in person data collection is called for. Issues raised when conducting recommended autism screening is a case in point. While validating the decision supports to efficiently complete the required M-CHAT Follow Up Interview (M-CHAT-R/F) as noted earlier[41], we discovered that the predictive validity of the M-CHAT-R/F was lower at the 18 month visit than at 24 months and saw that Pandey[53] had found the same. In order to understand why that may be happening we were able review de-identified M-CHAT data available on over 70,000 patients and determine that many items of the M-CHAT are on the cusp of typical development for 18 month olds such that using the same scoring method for both ages as recommended for this tool and for routine screening [15] and contributed to an excess of failed items for these younger children [54]. Our group has since been focusing on solutions to this problem through validation studies using a network of CHADIS using practices in Maryland affording over 5,500 screened children coming for their 18 month checkup. Since

we know from prospective studies [55] that autism symptoms are just emerging at this age, one approach we have explored was to use items that were unlike the yes/no format of the M-CHAT but rather asked the parents “how much”. When we rescored two very brief existing tools and used them together the result was better sensitivity (0.62) for autism diagnoses than the M-CHAT-R/F (sensitivity of 0.48) without the need for a follow-up interview and this is the best current alternative[56]. Yet the positive predictive value problem has not been solved (only 0.37 and 0.32)[56]. However, our preliminary studies show predictive validities equal to the 24 month visit using an algorithm featuring the addition of some standard language items with varying pathways depending ongoing item scoring by the computer [57]. While paper tools require simple manual scoring, computerized tools are no more difficult to use when scoring is complex. Replication of this exciting approach is nearing completion with young toddlers identified by the Maryland CHADIS network through standard of care IRB formally exempted screening with some 340 now having completed diagnostic testing and additional non-standard screening items. A national intervention study on the efficacy of the Asthma PST using 24 CHADIS using practices and another aimed at evaluation of the Family Stress PST are now beginning. The CHADIS national network is available for studies by outside groups with research programs judged to be consistent with the mission of CHADIS, and approved by its non-profit Center. Investigators from Boston Children's Hospital and the University of Colorado are now in the planning stage with custom research tools being created.

Other aspects

Privacy and Security—When patients enter responses or free text into CHADIS questionnaires data is instantly sent to central servers and no data is retained on the device used, blocking the possibility of data breaches from loss or theft of devices. CHADIS's highly secure servers are encrypted and all data collection and transmission is HIPAA and HITECH compliant. Clinicians can check a box to make any field of notes or any CHADIS report visible only to themselves in the future, affording very specific privacy for highly confidential information not possible with paper and many EHR records.

EHR Integrations—A CHIPRA demonstration grant to North Carolina concluded that no existing EHR was found to be compliant with the AHRQ Model Pediatric EHR Format [58] unless CHADIS was used as the “missing link” to meet the standards set by the Model. This initiative motivated some EHRs to integrate with CHADIS. CHADIS has an HL-7 interface and a custom API and integration has been accomplished with several EHRs (Allscripts Touchworks, Allscripts Pro, Office Practicum, eClinicalWorks and Athena with Physician's Computer Company (pending) through partnerships as well as one-off instances of integration with Centricity, EPIC, and Cerner. An EPIC FHIR integration is underway. The format of integrations vary from results appearing as lab results to flow sheets within specific fields in the EHR encounter note. Patients enter data directly in CHADIS in some integrations or within the EHR portal in others. In some cases the patient is reminded by a text or email from CHADIS to complete questionnaires and in other cases the reminder is within the EHR portal.

Conclusions

Use of a comprehensive panel of online pre-visit screens, linked decision support to provide moment-of-care training, and post-visit activities and resources for patient-specific education, monitoring and care coordination is an efficient way to make the entire process of screening and follow up care feasible in primary care. CHADIS uniquely fulfills these requirements and provides Maintenance of Certification credit to physicians as well as added income for screening efforts.

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