Screening Strategies for Autism Spectrum Disorders in Pediatric Primary Care

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ABSTRACT: Background: Two strategies have been proposed for early identification of children with autism spectrum disorders (ASD): (1) using a general screening tool followed by an ASD-specific screening tool for those who screen positive on the former or (2) using an ASD-specific tool for all children. The relative yield of these two strategies has not been examined. Objectives: This study compared the number of children identified at risk for ASD at their well child visits between the ages of 18 and 30 months using a general developmental screening tool and an autism-specific screening tool. Methods: The Parents' Evaluation of Developmental Status (PEDS) was used as the general developmental screening tool and the Modified Checklist for Autism in Toddlers (M-CHAT) was used as the autism-specific tool. These tools were administered concurrently to 152 children. Results: Cross tabulations and χ^2 tests were used to determine the utility of the PEDS as the first step of a two-part screen for ASD. Of those who screened positive for developmental concerns on the PEDS (n = 38), 16% screened positive for ASD on the M-CHAT; of those who did not screen positive for developmental concerns on the PEDS (n = 114), 14% screened positive for ASD on the M-CHAT (p = .79). Conclusion: The PEDS missed the majority of children who screened positive for ASD on the M-CHAT, suggesting that these two tools tap into very different domains of developmental concerns. The findings support the use of an ASD-specific tool for all children in conjunction with regular standardized developmental screening.

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Autism spectrum disorders (ASD) are a collection of developmental disorders that have in common deficits in socialization, communication, and repetitive or stereotyped behavior.¹ To meet diagnostic criteria, symptoms must be present before the age of 3 years. Symptoms often are apparent, however, before the age of 2 years.^{2,3} Recent epidemiologic studies have confirmed that ASDs are more common than previously thought, with a rate of 3 to 6 per 1000 children commonly reported,⁴⁻⁹ and the most recent estimates as high as 6.7 per 1000.¹⁰

Identification of children with ASD before the age of 3 years is very important, because earlier treatment initiation results in improved outcomes^{11–14} and decreased stress for families.¹⁵ Studies suggest, however, that the average age of diagnosis is between 3 and 6

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years, with many children not diagnosed until they enter kindergarten. 9,12,16,17

Primary care pediatricians play a critical role in the process of identifying children at risk for ASDs because they have more frequent contact with children under the age of 3 years than other medical or educational professionals. Two strategies have been proposed for early identification of ASD in primary care. General developmental surveillance, followed by ASD-specific screening for those who screen positive, was proposed by a multidisciplinary consensus panel after systematic analysis of the literature. 12,18,19 A recent policy statement from the American Academy of Pediatrics made a different recommendation, suggesting that general developmental surveillance be incorporated into every well-child visit followed by administration of a formal screening tool if risks are demonstrated, and autism specific screening at 18 and 30 months of age.²⁰ A variety of general developmental tools have been suggested for use in pediatric practice, in part because it has been shown that clinical impression is less accurate than formal screening.20 Such general developmental tools are appropriate for use in an unselected population due to their high sensitivity but low specificity. In other words, such tools are likely to identify children who have language and cognitive delay, but do not differentiate children whose delay is a function of an ASD from those whose delay may be due to mental retardation or to a specific language disorder.

Because of this, the American Academy of Pediatrics also recommends that all children receive autism specific screening at 18,²⁰ 24, and 30 months of age²¹ regardless

of the results of the general developmental surveillance. These ages were selected for a number of reasons. By definition, onset of symptoms of ASD occurs before age 3 years (except for childhood disintegrative disorder).1 About one third of children with ASD will show developmental regression some time between 18 and 30 months, which means that multiple screenings before the age of 3 years may be necessary.²²⁻²⁵ In addition, studies have shown that a diagnosis of autism may be reliably made by experienced clinicians when children are 2 years old, suggesting the benefit of screening before and at 2 years of age.²⁶⁻³⁰ There are no published data, however, regarding the yield of ASD-specific screening on its own, rather than as a follow-up to positive findings from a general developmental screen. Empirical comparison of these strategies is important because of the additional costs associated with separate screenings for ASDs.

To provide data on the relative efficacy of ASD-specific screening strategies, this study compared the number of young children (those having their 18-30 month wellchild visits) who were identified using a general screening tool as having developmental concerns that would generate further evaluation using an ASD-specific tool with the number of children who would be identified using an ASD-specific screening tool as a first-line screening tool. The Parents' Evaluation of Developmental Status (PEDS) was used as the general developmental screening tool and the Modified Checklist for Autism in Toddlers (M-CHAT) was used as the autism-specific tool. The PEDS was chosen because it was the choice of the pediatric primary care center where the study was being conducted. The primary care center had recently completed a clinical study examining the efficacy of implementing the Ages and Stages Questionnaire. The providers wanted to examine an alternate tool with open ended-questions such as the PEDS to see if it would be easier to implement. The clinicians were interested in assessing whether an open-ended tool would yield more accurate information about developmental problems.

This study was approved by the Institutional Review Boards of The Children's Hospital of Philadelphia and the University of Pennsylvania.

METHODS

Setting

The study was conducted at one of four pediatric primary care centers of The Children's Hospital of Philadelphia. The urban center at which the study was conducted has a caseload 5900 capitated patients, which results in 1800 patient visits per month. About 25% of scheduled patients were in the target age range of 18 to 30 months.

Sample

Families were eligible to participate if they had a child between the age of 18 and 30 months who was scheduled for a routine well-child visit between October 2005 and February 2006. Eligible participants were selected from the caseloads of the nine attending physicians who agreed to participate in the study and attended an education session on developmental screening. One attending physician whose employment began after we had conducted our educational session was not included in the study. Three additional physicians were part of the practice but only worked part-time and declined to participate. A research assistant approached the parent of each child in the examination room, described participation in the study, and obtained informed consent. Participating parents completed both the Parents' Evaluation of Developmental Status (PEDS) and Modified Checklist for Autism in Toddlers (M-CHAT). In most cases, the parent was able to complete the forms independently, but in some instances (n = 11; 7.2%) the research assistant read the questions to the parent and recorded the answer. This occurred because the caregiver had difficulty with written English or had a child whose behavior required their constant physical attention.

Three hundred six children were scheduled for a well-child visit with one of the nine physicians. Of this group, 87 children were not included because the parent cancelled or did not show for the visit and another 42 were not included because a research assistant was not available during their visit. Of the remaining 177 parents of children who were asked to participate, 22 refused and three were seen by nonparticipating physicians. The final sample included the remaining 152 children.

Measures

Parents' Evaluation of Developmental Status

The PEDS is a 10-item open-ended parent-completed questionnaire designed to elicit developmental concerns from caregivers of children from birth through 8 years of age.31 Parents may respond to each item with "yes," "a little," or "no" and then are asked to elaborate. The score and interpretation forms guide clinicians regarding further actions. Responses to the PEDS are divided into two categories: predictive or nonpredictive concerns. Predictive concerns refer to developmental issues that have been shown to correlate with developmental disabilities, whereas nonpredictive concerns are not significantly correlated with developmental disabilities. The five categories of predictive concerns included global/cognitive, expressive language, receptive language, social-emotional, and other. The PEDS was validated on a sample of 771 families with children aged 0 to 8 years across five US sites, encompassing urban, rural, and suburban areas. The validation sample was drawn from educational sources and pediatric clinical practices, and included families with a range of demographic and socioeconomic characteristics. To assess validity, the presence or absence of predictive concerns was compared with the presence or absence of disabilities, as measured by a concurrent battery of age appropriate diagnostic tests. The reported sensitivity is 74% to 79% and the specificity is 70% to 80%.32

Modified Checklist for Autism in Toddlers

The M-CHAT is a modified version of the Checklist for Autism in Toddlers (CHAT) which has 23 questions including nine parent-response questions from the CHAT³³

Table 1. Comparison of Disposition on the Parents' Evaluation of Developmental Status with the Six Critical Items from the Modified Checklist for Autism in Toddlers

M-CHAT Critical Item	PEDS		
	Pass	Fail	Total
Does your child like to be around other children or show interest in them? (Fisher exact test, $p = .57$)			
Yes	111 (97.4%)	38 (100%)	149
No	3 (2.6%)	0 (0.0%)	3
Total	114	38	152
Does your child ever use his/her pointer finger to point, to show interest in something? (Fisher exact test, $p = .34$)			
Yes	108 (94.7%)	38 (100%)	146
No	6 (5.3%)	0 (0.0%)	6
Total	114	38	152
Does your child ever bring things over to you to show you something? (Fisher exact test, $p = 1.0$)			
Yes	113 (99.1%)	38 (100%)	151
No	1 (0.9%)	0 (0.0%)	1
Total	114	38	152
Does your child imitate you? (e.g., if you make a face—will your child imitate it?) (Fisher exact test, $p = 1.0$)			
Yes	106 (93.8%)	36 (94.7%)	142
No	7 (6.2%)	2 (5.3%)	9
Total	113	38	151
Does your child respond to his/her name when you call? (Fisher exact test, $p = 1.0$)			
Yes	112 (98.2%)	37 (97.4%)	149
No	2 (1.8%)	1 (2.6%)	3
Total	114	38	152
If you point at a toy across the room, does your child look at it? (Fisher exact test, $p=1.0$)			
Yes	113 (99.1%)	37 (100%)	150
No	1 (0.9%)	0 (0.0%)	1
Total	114	37	151

The p values were not corrected for multiple comparisons for these tests. PEDS, Parents' Evaluation of Developmental Status; M-CHAT, Modified Checklist for Autism in Toddlers.

and 14 additional parent-response questions relating to symptoms present in very young children with autism. These additional questions were designed to replace the items on the CHAT that require observation by a clinician. The authors of the M-CHAT suggest that it be used as a screen for children 24 months of age to identify children who may have regressed between 18 and 24 months and to take advantage of the likely age at which pediatricians may be screening. The 23 M-CHAT items require "yes" or "no" responses from parents.

For validation, the M-CHAT was administered to 1293 children recruited from pediatricians and family practitioners (ages 18–24 months), and early intervention providers (ages 18–30 months) in Connecticut, United States. The sensitivity is reported to be 87% and the specificity 99% in the referred sample (i.e., children already identified as having developmental concern); data collection on a sample of children that were not referred is ongoing.³⁴ Six critical items (Table 1) were identified by discriminant

function analysis to maximize sensitivity of identification of risk for diagnosis of autism spectrum disorder (ASD), with a cutoff of two items providing the previously noted sensitivity and specificity.³⁴

Analysis

Descriptive statistics, including mean age and age range of children and parents, percentage of male and female children, and racial composition of the sample were computed. The proportion of parental concerns on the PEDS was calculated for the two categories of concerns: predictive and nonpredictive. Cross-tabulations of PEDS and overall M-CHAT scores were computed along with the χ^2 test of significance. Cross-tabulation of PEDS scores by the six "red-flag" or critical items on the M-CHAT were computed and tested using Fisher's- exact test. Positive and negative predictive values were also computed. All data analysis was performed using SPSS 12 and SAS 9.1 statistical software.

Table 2. Parents' Evaluation of Developmental Status Domain Breakdown by Parents' Evaluation of Developmental Status Paths Identifying Risk for Developmental Delays

Concern Area	One or More Predictive Concerns (N = 38)	No Predictive Concerns (N = 20)
Global/cognitive ^a	2 (5%)	0 (0%)
Expressive language and articulation ^a	29 (76%)	0 (0%)
Receptive language ^a	9 (24%)	3 (15%) ^b
Fine-motor	2 (5%)	5 (25%)
Gross-motor	4 (10%)	3 (15%)
Behavior	19 (50%)	13 (65%)
Social-emotional ^a	12 (32%)	3 (15%) ^b
Self-help	3 (8%)	3 (15%)
School	4 (10%)	2 (10%)
Other ^a	2 (5%)	0 (0%)

Cells represent the number and percent of parents scored on PEDS paths and expressing particular concern about their child's development. The proportions are based on this sample. *Predictive concerns. *bChildren were slightly under 18 month of age and for this age group these concerns were not predictive.

RESULTS

The mean age of the sample was 21 months with a range of 18 to 30 months. Fifty-seven percent of the sample was male. The racial/ethnic breakdown of the children was as follows: 42.1% Black, 30.9% White, 13.8% Asian, 10.5% Bi-racial, 3.2% Hispanic, and 0.7% in the "other" category. Mean age of mothers, who comprised 83% of respondents, was 28.1 years with a range of 17 to 52 years.

Table 2 presents the results from the Parents' Evaluation of Developmental Status (PEDS). All participating parents completed the PEDS. Sixty-two percent of respondents expressed no developmental concerns. Parents of 38% of children expressed some concern, 13% expressed nonpredictive developmental concerns, and 25% listed one or more predictive developmental concerns. Only those respondents who expressed concerns are represented in Table 2. These concerns fell into the domains of expressive language (n = 29; 85%), receptive language (n = 9; 24%) and social-emotional concerns (n = 12, 32%). Although predictive concern was not considered, 50% of parents with at least one predictive concern also endorsed concerns about behavior.

All participating parents completed the Modified Checklist for Autism in Toddlers (M-CHAT) and 14% of children screened positive. As shown in Table 3, of the 38 children who screened positive for predictive developmental concern on the PEDS, 6 (16%) screened positive for autism spectrum disorder (ASD) on the M-CHAT. Of the 114 children for whom the PEDS elicited no predictive concerns, 16 (14%) screened positive for ASD on the M-CHAT ($\chi^2 = 0.07, p = .79$). For these data, only 27% of those who screened positive on the M-CHAT had one or more predictive concerns on the PEDS. Of those who screened positive on the PEDS (one or more predictive concerns), only 16% (6 of 38) were identified as at risk for ASD on the M-CHAT. Of those who screened negative on

Table 3. Comparison of Results from Concurrent Administration of Parents' Evaluation of Developmental Status and Modified Checklist for Autism in Toddlers

PEDS	M-CHAT			
	Positive	Negative	Total	
One or more predictive concerns	6 (16%)	32 (84%)	38	
No predictive concerns/no concerns	16 (14%)	98 (86%)	114	
Total	22	130	152	

 χ^2 = 0.07. p = .79. PEDS, Parents' Evaluation of Developmental Status; M-CHAT, Modified Checklist for Autism in Toddlers.

the PEDS, 86% (98 of 114) were also negative on the M-CHAT. Thus, the proportion who were identified as at risk for ASD on the M-CHAT was about the same for those who screened negative on the PEDS as for those who screened positive.

Because of the high percentage of children screening negative on the PEDS and positive on the M-CHAT, we conducted post hoc analyses examining the association between specific red-flag items on the M-CHAT and disposition on the PEDS. As shown in Table 1, between 1% and 6% of children with a negative screen on the PEDS endorsed at least one critical item on the M-CHAT. In addition, of those who screened positive on the PEDS, 95% to 100% did not endorse critical items on the M-CHAT. Analysis using Fisher's exact test revealed no significant associations between positive findings on the PEDS and endorsing any of the M-CHAT critical items.

DISCUSSION

This study found that almost three quarters of children who screened positive for autism spectrum disorder (ASD) using an ASD-specific screening instrument did not elicit corresponding developmental concerns from their parents as measured by a standardized general developmental questionnaire. The data suggest that the Parents' Evaluation of Developmental Status (PEDS) and the Modified Checklist for Autism in Toddlers (M-CHAT) address different areas of developmental concern, and the general developmental screen may not adequately address concerns about social interaction or play. The results suggest that the general developmental screen examined in this study is not sufficiently specific to replace or be used as a first-stage screening tool for ASD.

Parents' responses to the questions on the PEDS suggest that they focus primarily on their children's behaviors, which did not differentiate children at risk from those not at risk. Next their responses focused on expressive and receptive language, and least frequently on their children's social interactions. Similarly, Coonrod and Stone³⁵ reported that parents of children with ASD were more likely to observe and report general developmental delays or regression in language skills rather than social or communication deficits. General developmental screening tools, especially those with open-ended questions, may therefore miss delays in the domains of social and communication skills that are important for the early

identification of ASD. The analysis of the association of critical social items from the M-CHAT with the PEDS underscores this point, with the overwhelming majority of children who scored positive on one or more of these items scoring negative on the PEDS.

Limitations and Recommendations

The calculation and estimations in this paper were based on the data from the sample. Generalizability of the findings is limited by the fact that data were collected from a single pediatric practice. English language proficiency was needed to complete the self-administered questionnaire. Language difficulties were a barrier in a small number of cases. The data collected through direct questioning of the parent may differ from that collected via self-administered forms due to nuances in translation and meaning. Finally, no further assessment of children was conducted to determine the presence of ASD using gold standard diagnostic tools for ASD. Only with this final diagnosis would it be possible to establish the criterion validity of the PEDS and the M-CHAT. Although it is possible that some or all of the children who screened positive for ASD on the M-CHAT do not meet diagnostic criteria for ASD, data from other studies suggest that it is highly unlikely that these children would be without any developmental concerns.36-38

Despite these limitations, there are important implications related to these findings. The social and communication delays addressed in ASD-specific screening tools do not seem to be captured by popular general developmental screening instruments. The Ages & Stages Questionnaires, an age-specific series of parent completed questionnaires, screens for concerns in communication, gross motor, fine motor, problem-solving, and personal adaptive skills. The questionnaires for the ages of concern for early identification of ASD, 18, 24, and 36 months, include questions for communication, concentrating on receptive and expressive language, and gestures (primarily pointing). The questions do not include crucial red flag questions for diagnosing autism, such as joint attention (such as proto-declarative pointing) and sharing enjoyment or interest in peers. Psychometric data about the ability of the Ages & Stages Questionnaires to detect ASD has not yet been published.39

Data from this study support the recent American Academy of Pediatrics guidelines, specifically, routine developmental surveillance, use of an established general developmental screening tool to further assess risk when indicated, and use of an ASD-specific screening tool at specified ages. Reliance on a general developmental tool to identify those children who should be evaluated for ASD will miss a substantial proportion of those who are at risk. Although general developmental screening tools have an important place in pediatric primary care, it is essential that pediatricians understand the unique presentation of behavioral symptoms that indicate a child is at risk for ASD and that they rely on standardized screening tools to elicit those symptoms.. Future studies might explore three additional areas: validating these findings against a standardized diagnostic assessment, determining

the sensitivity of other developmental screening tools to concerns on an ASD-specific tool, and considering better strategies for capturing social and communication concerns in general developmental screening practices.

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Literary Quotes

Difficulties Re-establishing Discipline

As has been noted previously in these spaces, despite the literary genius of William Shakespeare (1564–1616), he had little to say about the inner world of prepubertal children or their upbringing. Yet, some valuable illustrations of insight do occur. For example, in *Measure for Measure* the Duke Vincentio wishes to do a better job of enforcing his social laws, which he has been neglecting. He goes into hiding and turns the job over to a trusted lieutenant, Angelo, who goes too far, and thus the dramatic tension is created. This is how the Duke sees the situation at the outset.

"We have strict statutes and most biting laws,
The needful bits and curbs to headstrong jades,
Which for this fourteen years we have let slip;
Even like an o'er-grown lion in a cave
That goes not out to prey. Now, as fond fathers,
Having bound up the threatening twigs of birch,
Only to stick it in their children's sight
For terror, not to use, in time the rod
Becomes more mock'd than fear'd: so our decrees,
Dead to infliction, to themselves are dead,
And Liberty plucks Justice by the nose,
The baby beats the nurse, and quite athwart
Goes all decorum."

This is, of course, primarily a description of the civil disorder likely to occur when certain laws on social comportment are not enforced. However, pediatricians will note the reference to the indulgences of the fond father. When family rules have been allowed to be ignored, parents find it difficult to return to the "decorum."

In this play the Duke's deputy is too severe in resuming an enforcement of the law against fornication, resulting in some dark passages, but they are eventually resolved. The play is regarded as a comedy but that element comes mostly from some secondary characters with names like Elbow, Froth, Pompey, and Mistress Overdone.

Reference: Shakespeare W. Measure for Measure. Act I, Scene III, Lines 19-31; 1604.

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