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Diagnostic Evaluation of Autism Spectrum Disorder in Pediatric Primary Care

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Abstract

Background and Objectives: Children with autism spectrum disorder (ASD) continue to experience significant delays in diagnosis and interventions. One of the main factors contributing to this delay is a shortage of developmental-behavioral specialists. Diagnostic evaluation of ASD by primary care pediatricians (PCPs) has been shown to be reliable and to decrease the interval from first concern to diagnosis. In this paper, we present the results of a primary care ASD diagnosis program in which the PCP serves as the primary diagnostician and leverages the infrastructure of the primary care medical home to support the child and family during the pre- and post-diagnostic periods, along with data on parental satisfaction with this model. **Methods:** Retrospective data from a cohort of patients evaluated through this program were analyzed to determine the mean age at diagnosis and interval from referral for evaluation to diagnosis. We used survey methodology to obtain data from parents regarding their satisfaction with the process. **Results:** Data from 8 of 20 children evaluated from April 2021 through May 2022 showed a median age of diagnosis of 34.5 months compared to the national average of 49 months. Mean interval from referral for evaluation to diagnosis was 3.5 months. Parental survey responses indicated high satisfaction. **Conclusions:** This model was successful in shortening the interval from referral to diagnosis resulting in significant decrease of age at diagnosis compared with the national average. Widespread implementation could improve access to timely diagnostic services and improve outcomes for children with ASD.

Keywords

primary care, health outcomes, health inequities, access to care, patient-centeredness

Introduction

Despite compelling evidence for the importance of early intervention for children with autism spectrum disorder (ASD),[1] most of these children experience delays in diagnosis and in initiation of interventions after initial reported concerns.[2] These delays represent a loss of time during the physiological window of maximum brain plasticity when interventions are most effective.[3] One contributing factor to this problem is the long waiting time to access the specialists who typically perform diagnostic assessments for ASD.[2,4] The combination of increased demand for evaluation and the relatively small number of professionals trained to meet it create a bottleneck effect,[4,5] with some areas reporting wait times of over a year.[6] While the time between parents' initial concern and their child receiving a formal diagnosis is gradually shrinking, families still experience an average wait time of over 5 months (ranging from 0–24 months) before the diagnosis is given.[7] As a result, average age at diagnosis is 49 months,[8] despite data indicating that a reliable diagnosis of ASD can be made as early as 18 months.[9] Given the vast body of literature demonstrating that early intervention is key to optimal outcomes for these children, the current system is profoundly failing them.

Access to ASD diagnosis is even more challenging for racial and ethnic minorities and other populations historically underserved by the healthcare system.[10] These groups have experience substantial delays beyond the average wait time of their peers in the majority.[10]Average age of diagnosis

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of ASD for African American (AA) children was 64.9 months compared to 49 months national average.[11] AA children are also 2.6 times less likely to get an ASD diagnosis on first specialty care visit.[12] Significant barriers to early diagnosis and services have been identified in rural areas including geographic distance between families and providers, low reliance on health care professionals and cultural characteristics.[13] Furthermore, specialist shortages are more evident in lower-income communities and communities of color that rely more heavily on Medicaid, as well as in rural areas.[14] Lower-income patients from racial or ethnic minority groups are less likely to be referred to specialists based on developmental monitoring.[15] Studies suggest that such disparities are correlated with factors such as immigration, economic, linguistic, employment, and transportation status,[16-19] fragmented primary care,[20,21] maternal education level,[22] and general prejudices held by clinicians.[23]

Various strategies to improve access to diagnostic assessment for children with ASD have been explored.[24,25] Several studies have examined the role of the primary care pediatrician (PCP) in assessing these children,[26,27] along with training and capacity-building strategies—such as case-based learning,[28,29] didactic lectures or workshops,[24,27,30] and shadowing[31]—for PCPs to perform diagnostic evaluation for ASD.

Training for pediatricians to perform this evaluation has been shown to increase their knowledge and self-efficacy[31-33] and to foster positive change in practice and in relationships with families.[27,31] Additionally, this approach has been shown to significantly reduce interval between initial concern and diagnosis[24] as well as travel time and overall cost.[31] Finally, studies show a high level of diagnostic agreement between PCPs and specialists.[24,27]

In response to the mounting need for access to timely diagnostic evaluation for children identified as at high risk of autism, the authors developed a model for integrating the diagnostic evaluation for autism in the primary care setting with the aim of expediting the diagnostic evaluation of children suspected to have autism thereby providing an opportunity for early interventions and improved outcomes. In this study, we report on this model, which involves training the PCP to serve as the primary diagnostician. It also uses the infrastructure of the primary care patient-centered medical home (PCMH) to support the child and their family during the pre- and post-diagnostic periods. We discuss training, implementation, and the preliminary outcomes of this model, as well as characteristics of the primary care PCMH that are uniquely positioned to provide prompt evaluations and ongoing support following diagnosis to ensure access to care. Finally, we present data on the program's impact on time to diagnosis and on parental satisfaction with care. Based on collective evidence for this model's effectiveness and feasibility in primary care, we propose its implementation as 1 strategy to expedite and enhance ASD diagnostics and access to care.

Methods

Model Conceptualization, Development, and Implementation

This study was conducted in an academic teaching clinic with 6 full time faculty pediatricians and 1 advanced practice provider, and around 17 000 annual visits. Establishing a system for ASD diagnostic assessment in primary care was built on 4 foundational components that help to ensure that families receive high quality evaluations and support. These are: physician training, identification of patients with concerns for ASD, evaluation procedures, and care coordination.

1. Physician training: Pediatricians have a strong foundation of knowledge of typical child development as well as considerable experience in caring for children with developmental differences. Specialized training in the diagnostic evaluation of ASD builds on this preexisting skill set. High-quality training in ASD diagnosis and care is readily available. The American Academy of Pediatrics' (AAP's) Autism Toolkit[34] provides guidance on application of the Diagnostic and Statistical Manual, 5th Edition, (DSM-5) diagnostic criteria for ASD, as well as information regarding comorbid conditions, recommended interventions, and parent education. Case-based learning is available through the Echo Autism community.[33] For this program, the physician received training in the administration of ADOS-2, considered to be the "gold standard" for the assessment of ASD. Other commonly used ASD assessment tools include the Screening Tool for Autism in Toddlers and Young Children (STAT)[35] and the Childhood Autism Rating Scale, Second Edition (CARS-2).[36] Both instruments were developed for use by a wide range of professionals, including pediatricians, and take a shorter time to administer, which makes them more suitable for a busy primary care practice. A positive score on the STAT or the CARS-2 is an indication for a comprehensive evaluation for ASD.
2. Identification of patients with concern for ASD: Surveillance and screening for ASD and other developmental disabilities is recommended by the AAP and is pivotal to early detection. Developmental screening tools have been shown to improve the detection rate of developmental disabilities.[32] The Ages and Stages Questionnaire (ASQ), a commonly used screening tool,[37] is used routinely in this program at 9, 18, and 24 months of age. The Modified Checklist for Autism in Toddlers—Revised with Follow Up (MCHAT-R-FU), a screener for ASD, is also administered at 18- and 24-month health supervision visits.[38]

Children can also be identified as having possible developmental delay or ASD if parents present with concerns about their child's development. Parental concerns are highly predictive of developmental challenges and should prompt further evaluation regardless of screener results.[39] Children presenting to the primary care setting with developmental profile suggestive of autism were referred for further evaluation to the primary care autism diagnostic clinic if their presentation was straight forward and uncomplicated. Children who had medical, behavioral, or other developmental complexity were referred to specialized evaluation, such as developmental behavioral pediatrics or autism center. Children older than 5 years were referred to specialty evaluation.

3. Evaluation procedures: In this program, the evaluation process was designed to occur over 3 successive office visits to allow time for both practitioner and family to process information and make decisions regarding care. The evaluation involved an initial diagnostic interview in the first visit, structured behavioral observation in the second visit, and feedback in the third visit. Ongoing care was provided at subsequent follow-up visits. All these visits were face to face and none of them happened via telehealth. There were no requests from the parents for telehealth visits.

Visit 1. A 1-h appointment was scheduled to complete an initial diagnostic interview with the parents or guardians. One or both parents were usually present with the child. Occasionally, a grand parent or an adult sibling of the child were also present.The interview included a thorough medical and developmental history and an evaluation for the core symptoms of ASD based on the DSM-5 criteria. A parent interview guide was developed by the author to ensure a comprehensive evaluation. If, based on the information gathered during this process, ASD was considered as a potential diagnosis, the child was scheduled for a structured behavioral observation using ADOS-2.

Visit 2. A 1-h appointment was scheduled a few weeks after the initial interview to complete a structured observation using ADOS-2. An additional hour was reserved immediately after the second appointment for the pediatrician to document observations, score the ADOS-2, and generate the diagnostic report.

Visit 3. A 45-min appointment was scheduled within 1 week of the ADOS-2 administration to provide feedback to the family. In addition to the diagnosis, prognosis, recommendations for intervention, anticipatory guidance, and follow-up were discussed with the family. Time was dedicated to providing emotional support and answering parent questions. Parents were also provided with a diagnostic letter that they can share with the school. After visit summary included educational information and lists of community resources were also provided. Following the physician encounter with the family, the patient care coordinator met with the family and provided them contact information for intervention services as well as contact information for the clinic's support line.

4. Care coordination: The infrastructure of the primary care PCMH model, which includes multidisciplinary teams of professionals (ie, pediatricians, nurses, behavioral therapists, and social and community health workers) who provide case management and care coordination, is ideal for supporting children and families before and after the diagnosis of ASD is established. Care coordination is often the role of social or community health workers, who help overcome barriers and navigate systems often unfamiliar to families. When screening indicates developmental concerns, care coordinators can assist with a referral to the state's Child Find network to initiate an evaluation for potential early intervention support. Following a diagnosis, best practice calls for ongoing support to access recommended services. Care coordinators may help families access resources for therapy (eg, Applied Behavior Analysis, behavioral health), insurance (eg, Medicaid), and long-term support (eg, disability waivers). They may also assist with accessing further assessment when needed (ie, to specialized providers for ambiguous cases) and assisting in the exchange of evaluation and therapeutic information.

For this retrospective observational study, we collected data on children evaluated for ASD through this program, including demographic and diagnostic data. Children evaluated from April 2021 through May 2022 were eligible for inclusion in the study. IRB (Institutional Review Board) approved the protocol.

During the study period, 20 patients were identified by the pediatricians and practitioners in the clinic and referred for evaluation through this program.As shown in the attrition diagram, Figure 1, 4 patients were referred for specialty evaluation after the first session because of identification of complicating factors including, Trisomy 21, severe motor delay, and significant medical complications secondary to prematurity. Additionally, children in whom a definitive diagnosis of autism or any other developmental condition was reached at the end of the evaluation was referred for specialty care. Figure 1 shows the attrition chart for the recruitment process. Eight parents

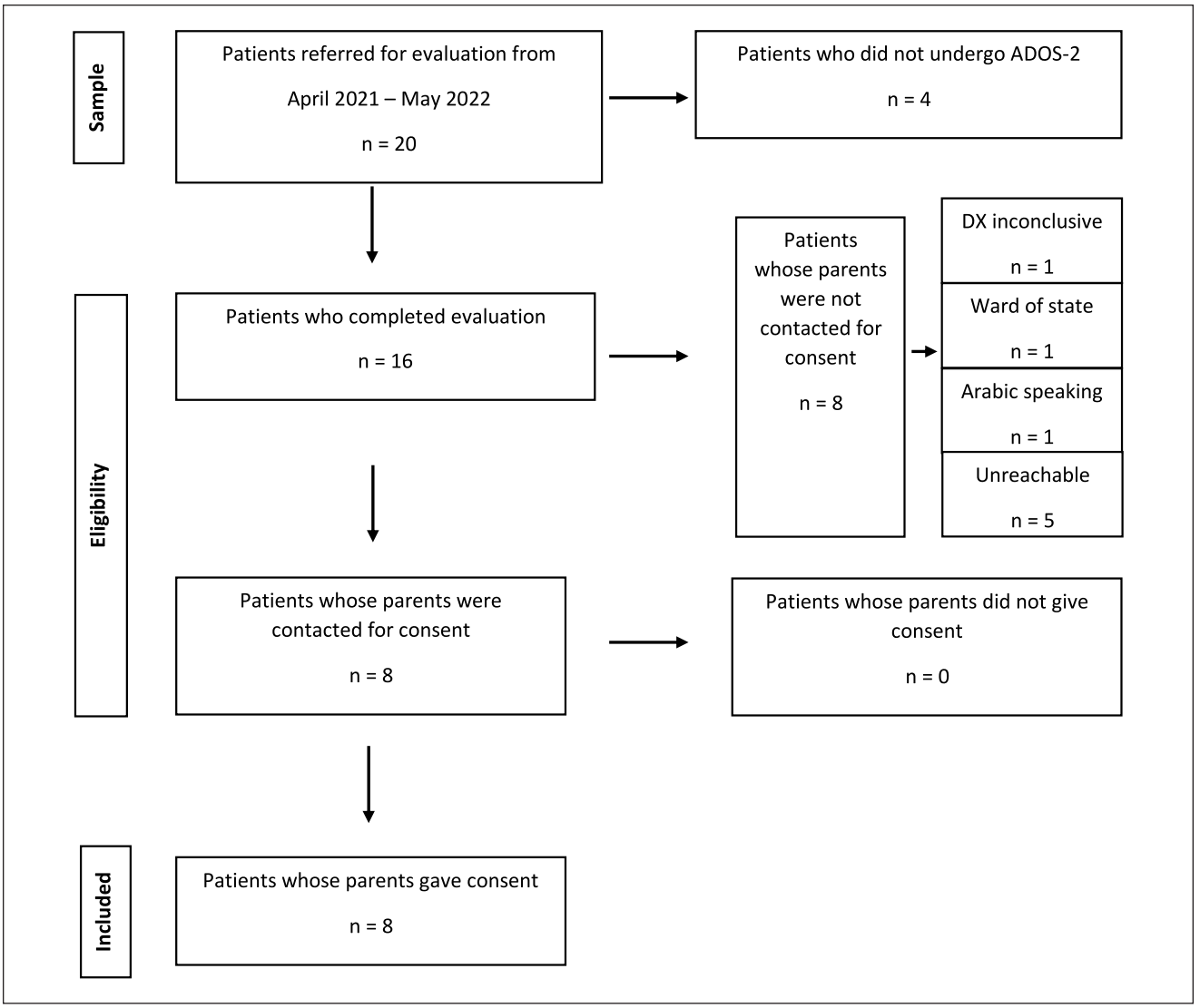

Figure 1. Recrutiment attrition chart.

consented to participate with their children. We conducted a manual EMR review to obtain information on the children's clinical characteristics, including age, gender, age at first concern, age at referral for ASD evaluation, and age at diagnosis, and evaluation outcomes. We also recorded the results of developmental screening instruments that included the ASQ and the M-CHAT. The parents completed a short questionnaire that was developed by the authors to evaluate the parents satisfaction with the evaluation process, focusing on their perception of the timeliness of the evaluation and satisfaction with the process and the support they received during and after the diagnosis The survey included 9 questions (Table 2). The results were identifiable to the research assistant who collected the answers but not to the PI. Parents rated their agreement with the questions on a 7-point Likert scale from strongly disagree (1) to strongly agree (7). "Characteristics of participating children and families were summarized using means and ranges for continuous measures and counts and percentages for categorical measures. Parent satisfaction was summarized using means and ranges of responses for each survey item."

Patient Demographic and Clinical Characteristics

The children enrolled in the study ranged from 19 to 49 months at time of referral. Three families identified as African American, 2 as Hispanic, and 3 as White. Two of the children were female and 6 were male. Mean age at documentation of first concern was 21.2 months (range

Table 1. Patient Data and Time to Diagnosis.

18 months			24 months							
ASQ language	ASQ social and emotional	M-CHAT	ASQ language	ASQ social and emotional	M-CHAT	Age of first concern[a]	Age at diagnosis[a]	Interval from first concern to referral for evaluation for autism[a]	Interval from referral to diagnosis[a] (evaluation)	Interval from first concern to diagnosis[a]
20 (F)	30 (F)	1	10 (F)	40 (P)	6	25	48	12	11	23
15 (F)	35 (F)	2	5 (F)	40 (P)	10	18	33	6	9	15
5 (F)	50 (P)	7	5 (F)	20 (F)	4	19	25	5	1	6
30 (P)	30 (F)	8	15 (F)	10 (F)	8	26	28	0	2	2
15 (F)	35 (F)	5	n/a	n/a	n/a	15	20	4	1	5
n/a	n/a	n/a	5 (F)	35 (F)	3	24	37	12	1	13
5 (F)	40 (P)	3	0 (F)	20 (F)	4	18	32	12	2	4
30 (P)	45 (P)	0	25 (F)	25 (F)	3	24	50	25	1	26

[a]Measured in months.

15-25 months). All children had been identified as demonstrating signs of ASD by their primary care pediatricians through developmental surveillance and screening; all were noted by their parents to have speech delay and tested positive for developmental delay by the ASQ. In all but 1 patient, parents reported behavioral concerns that were significantly disruptive to the family, including severe/prolonged tantrums, lack of eye contact, extremely picky eating, and aggressive behavior. Four children had elevated scores on the M-CHAT autism screener at 18 months, and 2 had subclinical scores on the M-CHAT at 18 months but had elevated scores at 24 months. M-CHAT was not available at 18 months for 1 child and at 24 months for another child. The results of the developmental profile on ASQ at 18 and 24 months are presented in Table 1. The mean interval between documented first concern and diagnosis was 13 months. Most of this time was a delay in referral for evaluation with a mean interval between first documented concern and referral was 9.5 months (range from 0-25 months). One child had a 25-month delay from first concern to evaluation, which seemed associated with lack of parental concern regarding developmental delays. All children were referred to the early developmental network for evaluation at time of first documented concern in the EMR. Mean age at diagnosis for this cohort was 34.5 months.

Parent Survey

All parents who consented to participate in the study completed the satisfaction survey (n = 8). Table 2 shows parents' responses to the survey question regarding their satisfaction with the evaluation processThe results of the survey indicate high parental satisfaction with the process.

Table 2. Parent Satisfaction Survey.

Questions	Patient average response
The evaluations were scheduled within a reasonable amount of time	6.750
The evaluation happened faster than I expected	6.000
The doctor explained things to me in a way I could understand	7.000
The doctor answered my questions	7.000
My child tolerated the evaluation	6.125
Follow up appointments were scheduled to answer my questions	6.750
I had the support I needed to get the services/ therapy the doctor recommended after the evaluation	6.750
I preferred to do this evaluation in our primary care office	6.500
Overall, I am satisfied with how the evaluation was done	6.250

Average parents' responses to Likert scale satisfaction survey: 1 corresponding to "strongly disagree" and 7 corresponding to "strongly agree."

Discussion

There is an urgent need for new models of care to provide timely access to ASD diagnostic services. The PCMH model of care delivery provides the infrastructure to integrate these services into the primary care setting by incorporating interdisciplinary teams of professionals who work together to provide diagnostics, care coordination, and continuity of care.[40,41] This model has been shown to improve access, decrease fragmentation of care, and improve management of chronic conditions.[42]

The accuracy of ASD diagnostic evaluations completed by pediatricians in the primary care setting is well documented.[24,27,43] A 2021 review of physician training programs found that training PCPs to diagnose ASD leads to high diagnostic agreement with specialty teams' assessments and reduces wait times.[44] PCPs can easily acquire the skills necessary to make an accurate diagnosis for children with clear ASD symptoms; in cases that are unclear or involve medical, behavioral, or social complexities, referrals to specialized providers should still be made. Integration of diagnostic services in primary care can also improve access to these services for children from racial and ethnic minority groups.[45]

In this paper, we describe a model of integrated diagnostic evaluation of ASD in pediatric primary care PCMH, where 1 pediatrician trained in the administration of ADOS-2 performed evaluations of children identified through developmental surveillance and screening. This program significantly shortened the interval from first concern to diagnosis for a group of racially and ethnically diverse children, achieving a mean age at diagnosis of 34.5 months compared to the national median of 49 months in 2022.[8] While this represents a significant improvement, there was still an average of 13 months delay from documentation of first concern for autism and diagnosis. Most of this delay was due to delayed referral to evaluation by the primary care physician. In this study, the average age of documented first concern was 21 months, compared to results of 2017 cross-sectional national survey showing only a minority of children are identified before 3 years of age, and a third to half of children are identified first after 6 years of age, when they are enrolled in school.[46] Earlier average identification in our sample may be a function of routine screening of all children between 18-30 months of age. Routine screening for autism in primary care is recommended by the AAP,[9,34,47] however, adherence to the recommendations may vary across geographical locations and over time. More studies need to explore the barriers to early identification and referral for evaluation by the primary care doctors.

Additionally, the parents of the children served through this program reported a high level of satisfaction; this is likely associated with both the speedy evaluation process and access to support following diagnosis. Previous studies have identified substantial frustration and uncertainty reported by parents after receiving a referral to a specialist due to long waitlists and their perceptions of loss of valuable time.[48,49] On the other hand, our evaluation's timeline over 3 sessions separated by a few weeks each was intended to give the parents the opportunity to process the information and adjust to the possibility of the diagnosis. The literature documents that real or perceived "speedy" time to ASD diagnosis was associated with mothers' unresolved reactions[50] and that support through care coordination can reduce caregiver burden and improve outcomes following diagnosis.[51]

The primary care PCMH offers unparalleled opportunities for access and continuity of care, which is advantageous for the seamless movement from identification through diagnosis to post-diagnostic care. The pediatrician also has a chance to follow the child's progress and observe the intervention's impact on development. Importantly, the medical home can help provide the emotional and social support network needed by the child and their family. The continuity of care in the PCMH allows the pediatrician to continue to monitor the family at close intervals, providing education and aid, when the family is not yet ready to consider the diagnosis of ASD.

Conclusions

The PCMH provides a readily available structure for early identification and evaluation of ASD and other developmental disabilities through providing access, care coordination, and continuity of care. PCPs can leverage their pre-existing knowledge of development and their long-standing relationships with patients' families to provide high-quality, reliable diagnostic evaluations for children with uncomplicated ASD. Our program was successful in meeting the diagnostic needs of our ethnically and culturally diverse patient population by an average of 32 months of age, thus providing access to early intervention and potentially improved outcomes.

This is a pilot project describing the feasibility of implementation of this program and the outcome of a small sample of children evaluated by the program. More studies are needed to test this concept with a larger sample and explore issues of sustainability and scalability as well as adaptation to global contexts.

Author Contributions

Drs. Arwa Nasir and Whitney Strong-Bak conceptualized and designed the study, and the data collection instruments, carried out the initial analysis, collected data, drafted the initial manuscript, and critically reviewed and revised the manuscript. Both authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work. Marie Bernard, BS participated substantially in data collection and prepared the first draft of the manuscript including the tables and figures. She also did a literature review and managed the references in the manuscript. She reviewed and approved the manuscript as submitted and agrees to be responsible for the content.

Declaration of Conflicting Interests

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