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Age of Autism Spectrum Disorder Diagnosis and Patient-Centered Medical Home Components

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Abstract

Early diagnosis of autism spectrum disorder (ASD) in children facilitates the provision of services and enhances opportunities for improving functioning via intervention**.** To date, limited studies have examined whether age of ASD diagnosis is associated with components of care of the patient-centered medical home (PCMH), a model of health care that emphasizes centralized, accessible, and coordinated care. The objective of the current study was to evaluate the associations between components of the PCMH and age of ASD diagnosis while controlling for associated clinical and socio-demographic factors, in a national sample of children 17 years and younger with ASD. The present study was a cross-sectional, observational study. Participants were caregivers of 1,193 children ages with ASD from the 2020 National Survey of Children's Health (NSCH). Hierarchical multiple linear regression analysis was run with age of ASD diagnosis as the criterion variable in two regression models. The binary composite medical home proxy variable was investigated as well as the five individual medical home components (usual source of care, personal doctor or nurse, family-centered care, care coordination, able to obtain referrals when needed). In the first regression analysis, the overall PCMH proxy variable was significantly correlated with the age of ASD diagnosis (standardized beta coefficient = −.08; $p < .01$). Of the five components of the PCMH assessed in the second regression model, only usual source of sick care was significantly associated with the age of ASD diagnosis (standardized beta coefficient = −.11; $p < .01$). Having a usual source of sick care may be an important factor in receiving an earlier ASD diagnosis for children and adolescents.

Keywords Autism spectrum disorder · Patient-centered medical home · Children · Diagnosis · Age

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social-communication deficits, and repetitive and restricted interests and behaviors that become present early in life. In the United States, 1 in 36 children have a diagnosis of ASD (Maenner et al., 2023). Early diagnosis of ASD facilitates the provision of services for this population and enhances opportunities for improving functioning via intervention (e.g., early intensive behavioral intervention for ASD; Zwaigenbaum et al., 2013, 2015). Advantages in adaptive functioning may be feasible through early intervention, in addition to producing benefits for parent and familial in terms of education and preparation (Zwaigenbaum et al., 2013). In one study, children diagnosed with ASD later (e.g., between 25 and 41 months old) demonstrated greater impairments in nonverbal reasoning, adaptive behavior, ASD symptom severity, fine motor skills, receptive language, and social skills compared to children with ASD diagnosed earlier (e.g., between 12 and 18 months old; Miller et al., 2021). These findings underscore the importance and implications of early diagnosis of ASD.

The patient-centered medical home (PCMH) is a model of primary care delivery that uses centralized, accessible, and coordinated care (CDC, 2021). This model stresses utilization of team-based care and a whole-person orientation through the use of improved access to a range of available providers intended to support the patient from multiple angles (Arend et al., 2012). While PCMH determination is typically made by an evaluation conducted by the health care organization, proxy measures have been developed and validated to allow caregivers to report on components of their child's care that are consistent with the PCMH model of care (Knapp et al.,

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2014). The PCMH is a promising avenue for addressing barriers associated with the healthcare system, in terms of quality, cost, and continuity of care, that can benefit outcomes for both patients and providers (Arend et al., 2012). This model of care is associated with greater primary care visits (Aysola et al., 2013) and fewer emergency room visits in general (David et al., 2015). Among children with ASD, receiving care in a PCMH is associated with fewer unmet health care needs, less parenting stress, and better maternal mental health (Limbers et al., 2020; Todorow et al., 2018).

The American Academy of Pediatrics recommends that routine developmental screening take place during well child appointments within the PCMH (American Academy of Pediatrics, 2021). Consistent with this recommendation, previous research has documented a positive relationship between developmental screening in the past year and receiving services in a PCMH in children 9–35 months (Hirai et al., 2018). These findings coupled with literature that indicates routine developmental screening was associated with earlier identification of ASD (Pierce et al., 2021) suggest children who receive care in a PCMH may be more likely to receive a timely ASD diagnosis. To date, limited studies have examined whether PCMH components are associated with age of ASD diagnosis. Barger et al. (2023) assessed the relationship between PCMH components, developmental screening, and a diagnosis of ASD. The overall PCMH proxy variable was not associated with a diagnosis of ASD under 5 years of age or under 5 years identified in the previous year. The study examined different components of the medical home and found that usual source of care was positively associated with ASD being diagnosed in the previous year. While this study provided important information about components of the PCMH and age of ASD diagnosis, there were some methodological limitations that limit the generalizability of the findings, the most noteworthy being the sample was limited to children with ASD under 5 years old and the analysis did not account for some important family-level variables (e.g., language spoken in the home). Consequently, the objective of the current study was to evaluate the associations between components of the PCMH and age of ASD diagnosis in a national sample of children 17 years and younger diagnosed with ASD. We hypothesized that the overall PCMH proxy variable would be associated with earlier age of ASD diagnosis. We also predicted that when examining the five components of the PCMH, the usual care component would be associated with earlier age of ASD diagnosis.

Material & Methods

Participants and Procedures

Participants in this sample were caregivers of 1,193 children with a diagnosis of ASD ages 17 years old and younger from the United States 2020 National Survey of Children's Health (NSCH). The 2020 NSCH included data on 42,777 children. For the purposes of this study, only children whose caregiver reported they currently had a diagnosis of ASD were included. Through the NSCH, parents completed questionnaires about their children online or by mail. Survey topics included socio-demographic characteristics, health insurance coverage, a proxy for PCMH care, type of provider who made the ASD diagnosis, receiving a behavioral intervention for ASD, and age of ASD diagnosis.

Measures

Information about the measures was taken from the 2020 National Survey of Children's Health SPSS Codebook for Data Users (CAHMI, 2022). The reader is referred to https://mchb.hrsa.gov/data-research/national-survey-childrens-health/nsch-questionnaires-datasets-supporting-documents to view specific items and response scales used in the 2020 National Survey of Children's Health in the current study.

ASD-Specific Factors

ASD diagnosis was based on caregiver responses to the questions, "Have you ever been told by a health care provider that [child] has autism or another autism spectrum disorder?" and, "Does [child] currently have autism or autism spectrum disorder (ASD) including Asperger's disorder, pervasive developmental disorder?" Children were included in our study if their caregiver responded, "yes," to the first question and, "currently has condition," to the second question.

Type of provider who made the ASD diagnosis was assessed with the question, "what type of doctor or other health care provider was the first to tell you that this child had autism, ASD, Asperger's, or pervasive developmental disorder?" Responses were categorized as: "primary care provider," "specialist," "psychologist or counselor," psychiatrist," or "other health care provider."

Age of diagnosis for ASD was determined by the question, "How old was the child when a doctor or other healthcare provider first told you that he or she had autism, ASD, Asperger's disorder, or pervasive developmental disorder?" Caregivers reported the age in years.

ASD severity was based on the question, "would you describe this child's current autism as mild, moderate, or severe?" Severity for ASD was categorized as: "does not currently have autism," "current autism rated mild," "current autism rated moderate," and "current autism rated severe."

Caregivers reported on whether the child received behavioral intervention for ASD. Responses were categorized as: "currently has condition and received behavioral treatment,"

"currently has condition but did not receive behavioral treatment," and "does not currently have condition."

PCMH

A proxy for PCMH care, developed as part of the Child and Adolescent Health Measurement Initiative (CAHMI), was used in the present study. This binary composite indicator has been extensively utilized in the peer-reviewed literature (Baron-Lee et al., 2015; Hadland & Long, 2014; Long et al., 2012; Stevens et al., 2011; Strickland et al., 2011) and is derived from 16 items that correspond to the five components of the American Academy of Pediatrics medical home definition. PCMH care was deemed present using the proxy variable if a caregiver endorsed that the child had a personal doctor or nurse, a usual source for care, and received family-centered care. In addition, children whose caregivers indicated they required care coordination, or a referral also needed to have been able to receive those components for PCMH care to be deemed present using the proxy variable. In addition to utilizing the overall composite proxy medical home variable in the current study, we also investigated the five individual medical home components (usual source of care, personal doctor or nurse, family-centered care, care coordination, able to obtain referrals when needed).

Health Insurance Coverage

The determination of continuous health care coverage was based on the following item: "Did this child have consistent health insurance coverage during the past 12 months?" Responses were categorized as: "Yes," or, "No."

Socio-Demographic Characteristics

Caregivers reported on their child's race/ethnicity, age, gender, language, and if their child was receiving free or reduced cost school lunch. The determination of the child's race/ethnicity was based on the question, "what is the child's race/ethnicity?" Responses were categorized as, "Hispanic," "White, non-Hispanic," "Black, non-Hispanic," "Asian, non-Hispanic," and "Other, non-Hispanic." Caregivers were asked, "what is this child's age?" Response options were, "0–3 years," "4–7 years," "8–11 years," "12–14 years," and "15–17 years." Gender was assessed with the question, "What is this child's sex?" Response options were "male" and "female." To assess primary language spoken by the child, caregivers were asked, "What is the primary language spoken in home?" Response options were "English" and "[language] other than English." Caregivers were asked, "has someone in the family received free or reduced-cost breakfasts or lunches at school at any time during the past 12 months?" Response options were "Yes" and "No."

Statistical Analysis

Data were analyzed in SPSS Version 28 (IBM Corp, 2021). Spearman rank correlations were run between age of ASD diagnosis, ASD indicators (severity and receiving ASD behavioral treatment), and socio-demographic characteristics. Child gender was coded as 0 = female and 1 = male; free or reduced lunch was coded as 0 = no and 1 = yes; child race/ethnicity was coded as 0 = non-White and 1 = White; ASD severity was coded as 1 = mild, 2 = moderate, and 3 = severe; receiving ASD behavioral interventions was coded as 0 = no and 1 = yes; language spoken in home coded as 1 = English and 0 = other; continuous health insurance coverage last 12 months was coded as 0 = no and 1 = yes. Spearman correlations were classified as 00–0.19 (very weak), 0.20–0.39 (weak), 0.40–0.59 (moderate), 0.60–0.79 (strong), and 0.80–1.0 (very strong; Schober et al., 2018).

Hierarchical multiple linear regression analysis was used. For the first regression model, age of ASD diagnosis was the criterion variable for the total sample. Socio-demographic variables (e.g., child age, primary language spoken in the home, race/ethnicity, receiving free or reduced lunch) and ASD symptom severity were entered into Model 1 as control variables. In Model 2, the overall PCMH proxy variable was added to determine if it incremented the variance explained in the final adjusted model for which age of ASD diagnosis was the outcome.

In the second regression model, age of ASD diagnosis was the criterion variable. Only participants whose overall care involved the five components on the PCMH proxy measure, including endorsing needing care coordination and referrals, were included in this regression model ($n = 366$). Socio-demographic variables (e.g., child age, primary language spoken in the home, race/ethnicity, receiving free or reduced lunch) and ASD severity were entered into Model 1 as control variables. In Model 2, the five components of the PCMH proxy measure (usual source of care, personal doctor or nurse, family-centered care, care coordination, able to obtain referrals when needed) were added to determine if they incremented the variance explained in the final adjusted model for which age of ASD diagnosis was the outcome.

Results

Participant Characteristics

Table 1 presents the socio-demographic characteristics of the sample. The mean age of the sample was 11.09 years (SD = 4.31). Participants were predominantly male (78.7%), English-speaking (94.6%), currently receiving behavioral interventions for ASD (58.3%), and had continuous insurance coverage over the last 12 months (94.4%).

Table 1 Socio-demographic characteristics of the sample ($n = 1{,}193$)

	M(SD)
Child Age	11.09 (4.31)
Child Age of ASD Diagnosis	5.06 (3.32)
	%
Gender	
Male	78.7
Female	21.3
Race/Ethnicity	
White	67.4
Non-White	32.6
Primary Household Language—English	94.6
Receiving Behavioral Treatment for ASD	58.3
Receiving Free or Reduced-Price Lunch	36.8
Care Meets PCMH Criteria	35.8
Continuous Health Coverage Last 12 Months	94.4

Approximately one third of participants (36.8%) were receiving free or reduced lunch. Regarding racial identity, 67.4% of the sample was White. Most children were first diagnosed with ASD by a specialist (35.9%). With regard to ASD severity, children were rated by their caregivers as mild (49.0%), moderate (39.8%), and severe (10.8%). Approximately one third of the sample (35.8%) had medical care that met the overall PCMH proxy criteria.

Spearman Rank Correlations

Age of ASD diagnosis was associated with the current age of the child ($r_s = .39$; $p < .001$), receiving free or reduced cost lunch ($r_s = .07$; $p < .05$), receiving ASD behavioral interventions ($r_s = -.07$; $p < .05$), race/ethnicity ($r_s = .14$; $p < .001$), primary language spoken in the home ($r_s = .08$; $p < .01$), and ASD symptom severity ($r_s = -.25$; $p < .001$). The overall PCMH proxy variable was associated with the current age of the child ($r_s = .13$; $p < .001$), receiving a behavioral treatment for ASD ($r_s = -.08$; $p < .01$), ASD symptom severity ($r_s = -.10$; $p < .001$), primary language spoken in the home ($r_s = .08$; $p < .01$), and race/ethnicity ($r_s = .08$; $p < .01$).

Hierarchical Multiple Linear Regression Analysis

Table 2 presents standardized beta coefficients for the hierarchical multiple linear regression analysis from the total model, which included all predictors. The variance explained by the total adjusted model for which age of ASD diagnosis was the outcome was significant ($p < .001$). In Model 1, socio-demographic variables and ASD severity significantly predicted age of ASD diagnosis ($p < .001$). By adding the overall PCMH proxy variable to the model, an additional 0.7% of the variance in age of ASD diagnosis was explained, and after controlling for child age, primary language spoken in home, race/ethnicity, receiving free or reduced lunch, and ASD severity, the overall PCMH proxy variable was significantly correlated with the age of ASD diagnosis (standardized beta coefficient = −0.08; $p < .01$).

Table 3 presents standardized beta coefficients for the hierarchical multiple linear regression analysis from the total model, which included all predictors. The variance explained by the total adjusted model for which age of ASD diagnosis was the outcome was significant ($p < .001$). In

Table 2 Hierarchical regression analysis overall PCMH proxy variable predicting age of autism diagnosis

Predictors	β	R^2	ΔR^2
Model 1		.237	
Child Age	.39***		
Primary Language Spoken in Home	−.01		
Race/Ethnicity	.09**		
Free or Reduced Price Lunch	.09**		
Autism Symptom Severity	−.21***		
Model 2		.244	.007**
Child Age	.40***		
Primary Language Spoken in Home	−.01		
Race/Ethnicity	.10***		
Free or Reduced Price Lunch	.09**		
Autism Symptom Severity	−.22***		
PCMH overall status	−.08**		

Free or reduced lunch was coded as 0 = no and 1 = yes; primary language spoken in home coded as 0 = Non English and 1 = English; child race/ethnicity was coded as 0 = non-White and 1 = White; ASD severity was coded as 1 = mild, 2 = moderate, and 3 = severe; overall PCMH proxy variable was coded as 1 = yes and 0 = no

***$p < .001$, **$p < .01$, *$p < .05$

Table 3 Hierarchical regression analysis PCMH 5 components predicting age of autism diagnosis

Predictors	β	R^2	ΔR^2
Model 1		.401	
Child Age	.52***		
Primary Language Spoken in Home	−.01		
Race/Ethnicity	.13**		
Free or Reduced Price Lunch	.10*		
Autism Symptom Severity	−.28***		
Model 2		.419	.018¤
Child Age	.53***		
Primary Language Spoken in Home	−.02		
Race/Ethnicity	.15***		
Free or Reduced Price Lunch	.10*		
Autism Symptom Severity	.29***		
Personal Doctor/Nurse	.02		
Usual Source of Sick Care	−.11**		
Family-Centered Care	−.07		
Referrals	−.01		
Care Coordination	−.03		

Free or reduced lunch was coded as 0 = no and 1 = yes; primary language spoken in home coded as 0 = Non English and 1 = English; child race/ethnicity was coded as 0 = non-White and 1 = White; ASD severity was coded as 1 = mild, 2 = moderate, and 3 = severe; had at least 1 personal doctor or nurse was coded as 1 = yes and 0 = no; usual source of sick care was coded as 1 = yes and 0 = no; received family-centered care was coded as 1 = yes and 0 = no; referrals coded as 1 = no difficulty getting referrals and 0 = difficult or not able to get referrals when needed; care coordination coded as 1 = received when needed and 0 = did not receive when needed

***$p < .001$, **$p < .01$, *$p < .05$; ¤ = $p = .05$

Model 1, socio-demographic variables and ASD severity significantly predicted age of ASD diagnosis ($p < .001$). By adding the five components of the PCMH to the model, an additional 1.8% of the variance in age of ASD diagnosis was explained. After controlling for child age, primary language spoken in home, race/ethnicity, receiving free or reduced lunch, and ASD severity, only usual source of sick care was significantly correlated with the age of ASD diagnosis (standardized beta coefficient = −0.11; $p < .01$).

Discussion

The present study assessed the associations between components of the PCMH and age of ASD diagnosis in a national sample of children 17 years and younger diagnosed with ASD.

As hypothesized, we found after controlling for socio-demographic characteristics and ASD severity, the overall PCMH proxy variable was negatively associated with age of ASD diagnosis. As such, having care that met the overall PCMH proxy criteria was associated with a younger age of ASD diagnosis. When we examined the associations between the five components of the PCMH (usual source of care, personal doctor or nurse, family-centered care, care coordination, able to obtain referrals when needed) and age of ASD diagnosis, usual source of sick care was the only indicator associated with age of ASD diagnosis. This finding is consistent with a recent study that found usual source of sick care delivered within the context of the PCMH was correlated with an ASD diagnosis in the last year in children with ASD under 5 years (Barger et al., 2023). Taken as a whole, these findings suggest having a usual source of sick care may be an important factor in receiving an earlier ASD diagnosis for children and adolescents and underscore the importance of encouraging caregivers to establish a usual source of sick care for their children. The findings also highlight the value of improving access to usual sources of sick care for children and their families. Numerous studies with adults have documented the benefits of having a usual source of care including greater receipt of preventative services such as vaccination against the flu (Toth et al., 2022) and cancer screening (Kim et al., 2012). In one study (DeVoe et al., 2009), children who did not have a usual source of care were more likely to not receive or experience delays in receiving needed medical, dental, or prescription care and caregivers reported more difficulties getting needed tests for their children. It is possible that the consistency of having a usual source of sick care for children provides greater opportunity for routine developmental screening, which has been identified as one factor associated with earlier identification of ASD (Pierce et al., 2021). It will be important for future research to elucidate the specific mechanism by which usual source of sick care may facilitate earlier age of ASD diagnosis.

In the present study, approximately two-thirds of children with ASD were not receiving care that met the overall PCMH proxy criteria. This is in line with previous research that suggests children with ASD are less likely to receive care in a PCMH (Todorow et al., 2018). Race/ethnicity was associated with the overall PCMH proxy variable in the current study. Specifically, children with ASD in our sample who were non-White were less likely to receive care that met the overall PCMH proxy criteria and less likely to have a usual source for sick care. Previous research align with current findings as non-White children were less likely to receive care in a PCMH due to reported lower odds of having a personal provider, a provider who allocated sufficient time with the child, communicated necessary information effectively, and were sensitive to family values (Raphael et al., 2009; Zickafoose & Davis, 2013). Altogether, minoritized children with ASD are faced with additional barriers when seeking and receiving care in a PCMH. Providers should be sensitive to family values,

time allocated to the patients, improve listening and communication skills, and working with parents in providing care to minority children with ASD (Raphael et al., 2009; Zickafoose & Davis, 2013). Based on the findings from the current study that indicate a usual source of sick care was the only component of the overall PCMH proxy criteria associated with earlier age of ASD diagnosis, it may be especially important for health care providers to encourage caregivers of racial minoritized youth to establish a usual source of sick care for their children. When families of racial minoritized youth are experiencing barriers to establishing a usual source of sick care, health care providers should help problem-solve ways to address those barriers.

The current study had a number of limitations. Given the cross-sectional nature, it is not possible to infer causation among the study variables. In addition, caregivers reported on the presence of their child's ASD diagnosis; there was no objective way to determine if children had received a diagnosis from a health care provider. Similarly, parents reported on the age of their child first being diagnosed with ASD, which may have been impacted by recall bias. Finally, determination of whether a child's care met the overall PCMH proxy criteria was based on 16 questions completed by caregivers; PCMH determination is typically made by an evaluation conducted by the health care organization given that caregivers may have more limited knowledge on how to evaluate PCMH components.

In conclusion, having a usual source for sick care, as essential component of the PCMH, was associated with an earlier age of ASD diagnosis in children. As such, a usual source of sick care may be a critical factor in receiving an earlier ASD diagnosis for children and adolescents.

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Data Availability Data and materials are available upon reasonable request from the first author.

Code Availability N/A.

Declarations

Conflict of Interest C. A. Limbers, T. Zeleznik, G. Beuley, A. Milliken, E. Hernandez, and S. R. Ryan-Pettes declare that they have no conflict of interest.

Ethics Approval Study procedures were approved by the Baylor University Institutional Review Board (IRB Net Identification number 2071284).

Consent to Participate All participants consented to participation in this research.

Consent for Publication The manuscript has been reviewed and approved by all authors and they have given necessary attention to ensure the integrity of the work and have agreed to it being submitted for publication.

Human and Animal Rights and Informed consent All participants provided informed consent and the study procedures were approved by the Institutional Review Board at Baylor University.

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