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Autism Spectrum Disorder Screening During the COVID-19 Pandemic in a Large Primary Care Network

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ABSTRACT

OBJECTIVE: To assess the impact of the COVID-19 pandemic on screening for autism spectrum disorder (ASD) and screening equity among eligible children presenting for well-child care in a large primary care pediatric network, we compared rates of ASD screening completion and positivity during the pandemic to the year prior, stratified by sociodemographic factors.

METHODS: Patients who presented for in-person well-child care at 16 to 26 months between March 1, 2020 and February 28, 2021 (COVID-19 cohort, n = 24,549) were compared to those who presented between March 1, 2019 and February 29, 2020 (pre-COVID-19 cohort, n = 26,779). Demographics and rates of completion and positivity of the Modified Checklist for Autism in Toddlers with Follow-up (M-CHAT/F) were calculated from the electronic health record and compared by cohort using logistic regression models.

RESULTS: Total eligible visits decreased by 8.3% between cohorts, with a greater decline in Black and publicly insured

children. In the pre-COVID-19 cohort, 89.0% of eligible children were screened at least once, compared to 86.4% during the pandemic ($P < 0.001$). Significant declines in screening completion were observed across all sociodemographic groups except among Asian children, with the sharpest declines among non-Hispanic White children. Sociodemographic differences were not observed in screen-positive rates by cohort.

CONCLUSIONS: Well-child visits and ASD screenings declined across groups, but with different patterns by race and ethnicity during the COVID-19 pandemic. Findings regarding screen-completion rates should not be interpreted as a decline in screening disparities, given differences in who presented for care. Strategies for catch-up screening for all children should be considered.

KEYWORDS: autism spectrum disorder; COVID-19; primary care; screening

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WHAT'S NEW

Well-child visits for young children and rates of autism-screening completion across a primary care pediatric network declined during the COVID-19 pandemic. Racial and ethnic differences in screening completion persist, but disparities narrowed slightly due to differences in well-child care receipt.

DURING THE CORONAVIRUS Disease of 2019 (COVID-19) pandemic, provision of well-child care declined in response to policies to limit infection¹ and parental concern about seeking non-urgent health care.² Ongoing surveillance and universal screening for autism spectrum

disorder (ASD) at 18- and 24-month visits are recommended to promote early detection and initiation of services.³ Prior to the pandemic, rates of ASD screening across the Children's Hospital of Philadelphia (CHOP) Care Network were high, with 91% of children screened at least once between 2011 and 2015. However, disparities in screening completion existed by race and ethnicity, family language, and socioeconomic status. Lower rates of having at least one screening were observed among children of Black (83.4%), Asian (91.6%), or multi-racial groups (91.8%) compared to White children (96.8%); those from lower income families (85.1%) compared to higher-income families (96.8%); those with public insurance (85.7%) compared to private (95.4%); and

those who spoke Spanish at home (83.6%) compared to English only (91.2%).⁴ Disparities in screening at both 18 and 24 months were even larger, in part because of differences in visit attendance.⁴

The COVID-19 pandemic also brought about and raised awareness of perpetual racial, ethnic, and socioeconomic disparities for children with respect to health care access and quality and patient outcomes, including disease incidence and death.⁵ While primary care offices in this study continued to prioritize well-child care visits for children under age 2 years and for those with missing vaccinations during the stay-at-home orders in March through May of 2020 consistent with American Academy of Pediatrics guidance, care for older children was often deferred early in the pandemic. One hospital system found that children who are Black or Hispanic, younger, and privately insured were more likely to present for care than other groups in 2020.⁶ However, the full impact of the COVID-19 pandemic on primary care provision and equity, including primary care's central role in ASD screening is incompletely understood.

We sought to examine the impact of COVID-19 on ASD screening in the CHOP Network by enumerating and comparing rates of 1) ASD screening completion for eligible children presenting for well-child care and 2) positive screens. The rates during the pandemic were each compared to baseline metrics from the year prior, stratified by sociodemographic factors.

METHODS

Patients who presented for in-person well-child care at 16 to 26 months of age (eligible screening ages, around the recommended 18 and 24-month visits) in the CHOP Care Network between March 1, 2020 and February 28, 2021 (COVID-19 cohort, $n = 24,549$) were compared to those who presented between March 1, 2019 and February 29, 2020 (pre-COVID-19 cohort, $n = 26,779$). The CHOP Care Network includes 29 sites in Pennsylvania and New Jersey that screen universally for ASD, using the Modified Checklist for Autism in Toddlers with Follow-up (M-CHAT/F).^{7,8} The M-CHAT/F, rather than the M-CHAT-R/F, is used across the Network, as the accuracy of these 2 versions is comparable⁸ and versions are often used interchangeably.⁹ Families are able to complete the screen electronically prior to the visit through an electronic patient portal, or on a tablet in the waiting room before the visit, with results auto-populating in the electronic health record (EHR) for provider review.⁴ Screening completion and results were extracted electronically from the EHR.

Sociodemographic data (sex, race, ethnicity, insurance type, and preferred language) were also gathered from the EHR in order to identify disparities in care. Race and ethnicity were categorized into the following groups: Asian; Black, non-Hispanic (hereafter referred to as "Black"); Hispanic or Latino; Other (which included multiple races); and White, non-Hispanic (hereafter referred to as "White"). Preferred language was classified as English or

Spanish. Families who did not speak English or Spanish ($n = 1137$) were excluded, as the screen is not yet available in other languages in the CHOP EHR. Primary insurance was classified as public (eg, Medicaid) or private.

Chi square tests were used to compare the sociodemographic characteristics of children presenting for well child visits between the 2 cohorts. Univariate logistic regressions were used to estimate odds ratios of screening completion and a positive screen comparing 2 cohorts, within each sociodemographic group. Multivariate logistic regression models were used to evaluate main effects for each sociodemographic characteristic, cohort, and an interaction between sociodemographic characteristics and cohort, adjusting for other potential confounders. The pre-COVID-19 cohort was the reference group for all cohort comparisons. Analyses were conducted using Stata, version 15 (StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC). This research was deemed exempt by CHOP's Institutional Review Board.

RESULTS

VISIT COUNTS

During the pre-COVID period, 26,779 well-child visits were completed among children eligible for ASD screening, compared to 24,549 during the COVID period, a decrease of 8.3% (Table 1). Racial composition of children presenting for care varied between cohorts ($P < 0.001$); the proportion of Black children decreased between the pre-COVID and COVID cohorts, while proportions of White Hispanic children, and "Other" race children increased. Children presenting for care during the pandemic were slightly more likely to be privately insured than pre-pandemic ($P = 0.048$). Cohorts did not differ with respect to age or other sociodemographic factors.

ASD SCREENING COMPLETION

For screening completion rates (Table 2), 89.0% of eligible children who presented for a well-child visit completed the M-CHAT/F screening pre-pandemic, compared to 86.4% during the pandemic ($P < 0.001$). In both cohorts, White, English-speaking, and privately insured children had higher rates of screening completion compared to all other racial and ethnic groups, Spanish-speaking, and publicly insured children, respectively. Rates of screening completion were significantly lower in the COVID-19 cohort than the pre-COVID cohort across groups, with statistically significant decreases for both sexes, all racial groups except for Asian children, children from English- and Spanish-speaking families, and children with both types of insurance. Multivariate logistic models produced significant main effects of both race and ethnicity and cohort on screening completion (Table 3). Their interaction terms were significant for Asian children (aOR, 1.37, 95% CI 1.07–1.76), Black children (aOR 1.17, 95% CI 1.01–1.37), and children of "Other" racial

Table 1. Demographic characteristics among eligible patients presenting for well-child care pre-COVID-19 and during COVID-19

	Total Eligible Visits (% of Total Annual Visits)		P-value
	Pre-COVID- 19 Cohort ^a	COVID- 19 Cohort ^b	
Total	26,779	24,549	N/A
Sex			0.07
Female	12798 (47.8%)	11929 (48.6%)	
Male	13981 (52.2%)	12620 (51.4%)	
Race and ethnicity			<0.001*
Asian	1194 (4.5%)	1122 (4.6%)	
Black, Non-Hispanic	5870 (21.9%)	4872 (19.8%)	
Hispanic or Latino	2442 (9.1%)	2324 (9.5%)	
Other	4046 (15.1%)	3864 (15.7%)	
White, Non-Hispanic	13227 (49.4%)	12376 (50.4%)	
Preferred language			0.91
English	26150 (97.6%)	23976 (97.7%)	
Spanish	627 (2.4%)	573 (2.3%)	
Insurance			0.048
Private	17735 (66.2%)	16460 (67.1%)	
Public	9044 (33.8%)	8089 (32.9%)	

^aPre-COVID- 19 Cohort (March 1, 2019 and February 29, 2020), Median age: 20.5 months, Total Eligible Visits = 26,779.

^bCOVID- 19 Cohort (March 1, 2020 and February 28, 2021), Median age: 20.3 months, Total Eligible Visits = 24,549.

*Statistically significant differences between proportions in COVID-19 cohort compared to pre-COVID-19 cohort.

groups (aOR 1.19, 95% CI 1.01–1.39). Overall, results indicate that 1) fewer Black children obtained well-child care during COVID-19 compared to other groups; however, 2) the decrease in screening completion during the pandemic was more pronounced among White children compared to Asian, Black, and “Other” race children, and thus 3) differences in screening completion by race and ethnicity were less pronounced during COVID-19 than before COVID-19. Other sociodemographic differences and interaction terms were not found statistically significant. To examine these trends, monthly rates in screening were visualized for both cohorts (Figure). In the pre-COVID-19 cohort, monthly screen-completion rates ranged from 86.5% to 92.7%, and in the COVID-19 cohort, from 76.0% to 90.8%. Noticeable discrepancies between 2 cohorts were seen before the reintroduction of tablets in waiting rooms.

ASD SCREENING POSITIVITY

In both cohorts, White, English-speaking, and privately insured children had lower rates of screening positivity compared to all other racial and ethnic groups, Spanish-speaking, and publicly insured children, respectively. There were no statistically significant differences in M-CHAT positivity between cohorts.

DISCUSSION

During the COVID-19 pandemic, the number of clinicians, practices, and overall patient population in the network remained stable. However, well-child visits declined slightly, with the most pronounced declines among Black and publicly insured children. Though high proportions (>75%) of all children were screened before and during the pandemic, screening completion rates fell during the COVID-19 pandemic in every racial and ethnic group except in Asian children (for whom screening decreases were not statistically significant, perhaps as a result of

smaller sample size of this group), with the most pronounced screening declines occurring among White children. This brought the overall screening completion rates across racial and ethnic groups closer to each other compared to pre-COVID-19. However, this should not be interpreted as a decrease in health disparities. Rather, it suggests that many children missed ASD screening, either because well-child care did not happen (eg, for a greater proportion of Black children), or because the ASD-screening portion of well-child care did not occur. Declines in well-child care for Black children during the pandemic are especially important to highlight and address, since other important components of well-child care beyond ASD screening may have also been missed. Black children experience both historic and contemporaneous barriers to high-quality health care,¹⁰ and also suffered disproportionately from COVID-19 in multiple ways.¹¹ These data add pressure to finding solutions to remedy both long-standing systemic injustices in health care receipt and the recent impacts of COVID-19.

As all screening was completed electronically, decreased use of tablets for electronic screening in the waiting room during the height of the pandemic might have contributed to these reductions in screening completion (Figure). Tablet use decreased as an infection-control policy introduced to reduce the sharing of equipment between patients and time spent in shared waiting rooms, particularly early in the pandemic when relatively less was known about methods of transmission. Tablet use for screening completion was resumed across sites in June 2020. Study practices saw increasing activation and reduced disparities in virtual patient portal access throughout the course of the pandemic (through which screening was available)¹²; these changes likely contributed to increases in screening completion by July 2020.

Competing personal priorities and additional responsibilities during the pandemic may have led to reductions in screening completion by caregivers (eg, families may

Table 2. Univariate logistic regression analyses for M-CHAT/F^a completion and M-CHAT/F positivity in the COVID-19 Cohort, compared to the pre-COVID-19 cohort in each sociodemographic group

	M-CHAT/F Complete Pre-COVID-19 Cohort ^b	M-CHAT/F Complete COVID-19 Cohort ^c	Unadjusted Odds Ratio for M-CHAT/F Completion comparing two cohorts (95% CI)	P-Value	M-CHAT/F Positive Pre-COVID-19 Cohort ^a	M-CHAT/F Positive COVID-19 Cohort ^b	Unadjusted Odds Ratio for M-CHAT/F Positivity comparing two cohorts (95% CI)	P-Value
Total	23,836/26,779 (89.0%)	21,200/24,549 (86.4%)	0.78 (0.74–0.82)	<0.0001	1,855/23,836 (6.9%)	1,705/21,200 (7.0%)	0.14 (0.97–1.11)	0.22
Sex								
Female	11406/12798 (89.1%)	10286/11929 (86.2%)	0.76 (0.71–0.83)	<0.0001	692/11406 (6.1%)	666/10286 (6.5%)	1.07 (0.96–1.20)	0.22
Male	12430/13981 (88.9%)	10914/12620 (86.5%)	0.80 (0.74–0.86)	<0.0001	1163/12430 (9.4%)	1039/10914 (9.5%)	1.02 (0.93–1.11)	0.67
Race and Ethnicity								
Asian	1023/1194 (85.7%)	957/1122 (85.3%)	0.97 (0.77–1.22)	0.79	111/1023 (10.9%)	103/957 (10.8%)	0.99 (0.75–1.32)	0.95
Black, Non-Hispanic	4946/5870 (84.3%)	3989/4872 (81.9%)	0.84 (0.76–0.93)	0.001	711/4946 (14.4%)	646/3989 (16.2%)	1.15 (1.02–1.29)	0.02
Hispanic/Latino	2131/2442 (87.3%)	1913/2324 (82.3%)	0.68 (0.58–0.80)	<0.001	287/2131 (13.5%)	243/1913 (12.7%)	0.94 (0.78–1.12)	0.47
Other	3578/4046 (88.4%)	3344/3864 (86.5%)	0.84 (0.74–0.96)	0.01	271/3578 (7.6%)	271/3344 (8.1%)	1.08 (0.90–1.28)	0.41
White, Non-Hispanic	12158/13227 (91.9%)	10997/12376 (88.9%)	0.71 (0.65–0.77)	<0.0001	474/12158 (3.9%)	442/10997 (4.0%)	0.13 (0.91–1.18)	0.64
Preferred Language								
English	23324/26150 (89.2%)	20786/23976 (86.7%)	0.79 (0.75–0.83)	<0.001	1761/23324 (7.6%)	1635/20786 (7.9%)	1.05 (0.98–1.12)	0.21
Spanish	512/627 (81.4%)	414/573 (72.3%)	0.60 (0.45–0.78)	0.0002	94/512 (18.4%)	70/414 (16.9%)	0.91 (0.64–1.27)	0.57
Insurance								
Private	16043/17735 (90.5%)	14454/16460 (87.8%)	0.76 (0.71–0.81)	<0.0001	691/16043 (4.3%)	643/14454 (4.5%)	1.03 (0.92–1.15)	0.55
Public	7793/9044 (86.2%)	6746/8089 (83.4%)	0.81 (0.74–0.88)	<0.0001	1164/7792 (14.9%)	1062/6746 (15.7%)	1.06 (0.97–1.17)	0.18

Bolded values indicate statistically significant differences between proportions in COVID-19 cohort compared to pre-COVID-19 cohort.

^aM-CHAT/F indicates Modified Checklist for Autism in Toddlers with Follow-up.

^bPre-COVID-19 Cohort (March 1, 2019 and February 29, 2020), Median age: 20.5 months, Total Eligible Visits = 26,779.

^cCOVID-19 Cohort (March 1, 2020 and February 28, 2021), Median age: 20.3 months, Total Eligible Visits = 24,549.

Table 3. Multivariate logistic regression analyses for M-CHAT/F^a completion and M-CHAT/F positivity adjusted for demographic factors, COVID-19 Cohort,^b as well as interaction terms between demographics and cohort

	M-CHAT/F Completion		M-CHAT/F Positivity	
	Adjusted Odds Ratio (95% Confidence Intervals, CI)	P-Value	Adjusted Odds Ratio (95% CI)	P-Value
Cohort				
Pre-COVID-19 Cohort	Reference	Reference	Reference	Reference
COVID-19 Cohort	0.69 (0.62–0.76)	<0.0001	1.08 (0.91–1.27)	0.38
Sex				
Female	Reference	Reference	Reference	Reference
Male	0.98 (0.91–1.06)	0.62	1.63 (1.28–1.80)	<0.0001
Interaction between cohort and sex				
Female*COVID-19 cohort	Reference	Reference	Reference	Reference
Male*COVID-19 cohort	1.05 (0.94–1.16)	0.40	0.94 (0.82–1.09)	0.44
Race and ethnicity				
Asian	0.53 (0.45–0.63)	<0.0001	2.81 (2.25–3.50)	<0.0001
Black, Non-Hispanic	0.51 (0.45–0.56)	<0.0001	2.33 (2.03–2.67)	<0.0001
Hispanic or Latino	0.76 (0.5–0.89)	<0.001	2.28 (1.90–2.74)	<0.0001
Other	0.69 (0.61–0.77)	<0.0001	1.66 (1.42–1.94)	<0.0001
White, Non-Hispanic	Reference	Reference	Reference	Reference
Interaction between Cohort and Race and Ethnicity				
Asian*COVID-19 cohort	1.37 (1.07–1.76)	0.01	0.95 (0.92–1.35)	0.76
Black, Non-Hispanic*COVID-19 cohort	1.17 (1.01–1.37)	0.04	1.11 (0.91–1.35)	0.31
Hispanic or Latino*COVID-19 cohort	1.00 (0.80–1.24)	1.00	0.91 (0.70–1.19)	0.50
Other *COVID-19 cohort	1.19 (1.01–1.39)	0.03	1.03 (0.82–1.29)	0.81
White, Non-Hispanic*COVID-19 cohort	Reference	Reference	Reference	Reference
Preferred language				
English	Reference	Reference	Reference	Reference
Spanish	0.56 (0.44–0.72)	<0.0001	1.19 (0.90–1.56)	0.22
Interaction between cohort and preferred language				
English*COVID-19 cohort	Reference	Reference	Reference	Reference
Spanish*COVID-19 cohort	0.82 (0.59–1.15)	0.25	0.92 (0.61–1.38)	0.69
Insurance				
Private	Reference	Reference	Reference	Reference
Public	0.88 (0.81–0.97)	0.008	2.78 (2.48–3.12)	<0.0001
Interaction between cohort and insurance				
Private*COVID-19 cohort	Reference	Reference	Reference	Reference
Public*COVID-19 cohort	1.03 (0.91–1.17)	0.64	1.00 (0.85–1.18)	0.98

Bolded values indicate statistically significant differences between proportions in COVID-19 cohort compared to pre-COVID-19 cohort.

^aM-CHAT/F indicates Modified Checklist for Autism in Toddlers with Follow-up.

^bThe COVID-19 Cohort (eligible children presenting for well-child care between March 1, 2020 and February 28, 2021) was compared to the Pre-COVID-19 Cohort (children presenting for well-child care between March 1, 2019 and February 29, 2020; reference group).

have chosen to focus on concerns they considered more urgent). Alternative strategies to promote screening completion by families should be considered. These might include use of reminders, such as text messages, to complete screening that are not linked to the patient portal or reminding families to complete the screen on a personal device while in the office. A population-based approach might also be considered, which could entail sending out screening questionnaires to all patients at 18 and 24 months, even without a scheduled visit, and prioritizing scheduling patients for visits who screen positive. These approaches may be particularly beneficial in situations that might otherwise limit screening, such as a pandemic.

The implications for these reduced rates of well-child care provision and ASD screening may be far-reaching if not acted upon. ASD-related concerns will need attention at future visits to identify children who were not screened and thus are at elevated risk for missed or delayed diagnosis. Furthermore, barriers to provision of face-to-face diagnostic and intervention services during the pandemic may also

limit the identification of ASD and delivery of therapies for eligible children.¹³ These reductions in screening and care may compound pre-existing racial, ethnic, and sociodemographic disparities in ASD identification and intervention.^{14,15} Lower rates of screening among children during the COVID-19 pandemic warrant attention.

LIMITATIONS

We were unable to examine the data for children who did not present for care during the pandemic; therefore, our findings may overestimate screening-completion rates of the entire practice population and may have excluded the groups of children at the highest risk of being unscreened (eg, selection bias). Our findings also may not generalize to practices without integrated electronic screening, or to patients with differential access to or comfort with electronic devices for screening completion. We only examined completion of one ASD screener; as in our prior work, even more children may have missed the second recommended screening at 24 months, which is

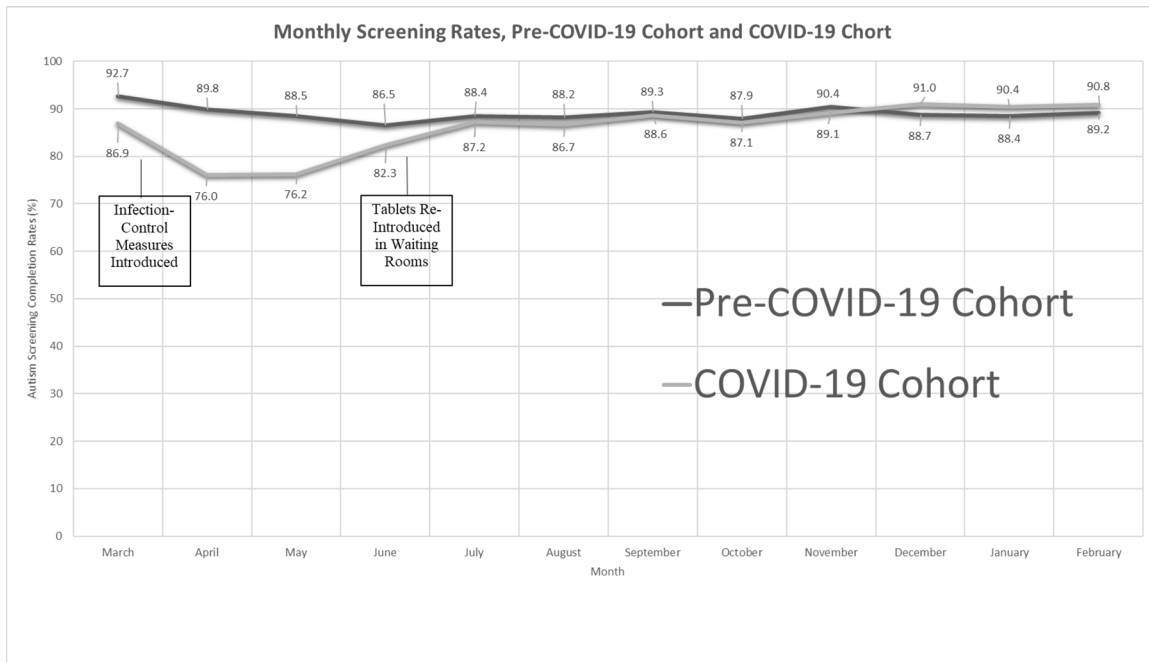


Figure. Monthly screening rates in the Pre-COVID-19 cohort (children presenting for well-child care between March 1, 2019 and February 29, 2020) and the COVID-19 Cohort (eligible children presenting for well-child care between March 1, 2020 and February 28, 2021), with important policy changes as noted.

important for improving ASD detection.⁴ Lastly, we did not examine longitudinal screening outcomes. Therefore, we cannot determine if patient care and screening were delayed beyond our study timeframe or missed entirely. Future work can examine site-level variation in screening to better understand the impact of site-specific processes.

CONCLUSIONS

The impact of the COVID-19 pandemic on children with ASD requires further study. We identified some decreases in well-child care, particularly for Black children, and decreased screening completion across most racial and ethnic groups. Strategies for catch-up may be needed to screen children who missed the traditional screening window. Screening tools, such as the M-CHAT-F, are validated up to 30 months. Practices may consider adding opportunities to screen up until that age if a child missed an earlier screen. Attention to the developmental needs of traditionally underserved populations, including minoritized racial and ethnic groups, non-English speakers, and publicly insured populations, remains critical to ameliorate persistent disparities.

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