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Mental Health Screening in Pediatric Primary Care for Children with Autism

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Abstract

Objectives: To report mental health screening rates in pediatric primary care as part of a larger program piloting Access to Tailored Autism INtegrated Care (ATTAIN), a model promoting timely identification of mental health needs and care linkage for children with autism.

Method: Data were extracted from the ATTAIN pilot in six pediatrics clinics within two organizations. Demographics and Pediatric Symptom Checklist-17 (PSC-17) data were collected during well-child visit appointments over four months for 166 children with autism ages 4–16 years.

Results: 53% (n=43) of 81 eligible children were screened in Organization 1 and 55% (n=47) of 85 of eligible children were screened in Organization 2. In Organization 1, 47% screened positive, as evidenced by an elevated PSC-17 Total Score, while 36% screened positive in Organization 2. Children with positive screens had elevations on the PSC-17 Externalizing and

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Attention subscales but not on the Internalizing subscale, confirming typical trends in co-occurring challenging behavior presentations in children with autism.

Conclusions: Slightly over half of eligible patients were PSC-17 screened. Positive screening rates were high, reinforcing the co-occurring nature of mental health needs in children with autism. Findings suggest opportunities to improve mental health screening in primary care for children with autism.

Lay Abstract

Children with autism experience high rates of co-occurring mental health conditions like challenging behaviors and anxiety. However, these co-occurring mental health needs are often not identified when they first become problematic. Pediatricians and their care staff are in a good position to identify mental health needs early and support families to connect to needed services. This study describes a project focused on mental health screening for children with autism in pediatric primary care clinics. Over half of eligible patients were screened using the Pediatric Symptom Checklist-17. Many children with autism had clinically elevated scores, suggesting the need for mental health assessment or services. In particular, children with positive screens had clinical elevations on the challenging behavior and attention subscales of the Pediatric Symptom Checklist-17. This finding is consistent with typical trends in co-occurring challenging behavior presentations in children with autism. Mental health screening in primary care is feasible and offers a promising opportunity to identify co-occurring mental health needs for children with autism early. Screening rates varied between clinics, suggesting tailored to improve routine screening in pediatric primary care for children with autism.

Keywords

mental health; screening; primary care; pediatrics; children; autism

Introduction

Co-occurring mental health problems among children with autism spectrum disorder (ASD) are highly prevalent and require lifespan, transdisciplinary and community participatory care approaches (Gotham et al., 2020). Pediatric primary care is a principal point of contact for children's healthcare and can be instrumental in first identifying and responding to mental health concerns before these needs escalate to significant impairment (Wissow et al., 2013). There is a recent call to consider screening for mental health as the "eighth vital sign" in pediatric well-child appointments (Jellinek & Murphy, 2021). Mental health screening in primary care may be particularly important for children with ASD given their high rates of co-occurring psychiatric conditions (Van Cleave et al., 2018). Limited research has examined *mental health* screening rates or prevalence for children with ASD in primary care.

The Access to Tailored Autism Integrated Care (ATTAIN) is a newly developed integrated care model to facilitate early identification of mental health needs and linkage to mental health care, tailored for school-age children with ASD and to diverse healthcare implementation contexts (Stadnick et al., 2019; Stadnick et al., 2020). As part of ATTAIN, primary care providers (PCPs) used the Pediatric Symptom Checklist-17 (PSC-17)

(Murphy et al., 2016), a brief mental health screener for children ages 4–16 years to identify mental health concerns in their patients who have an existing ASD diagnosis and use the information to formulate an appropriate clinical pathway. The ATTAIN model included eight general steps (described in Stadnick et al., in press) and three primary implementation strategies: (1) provider/clinic champions (Miech et al., 2018), (2) periodic reflections (Finley et al., 2018) and (3) technical assistance (Wandersman et al., 2012).

The purpose of the current study was to describe implementation patterns and initial outcomes of mental health screening and descriptive data on clinical characteristics of children with ASD screened using the PSC-17 within two organizations.

Method

This study used a cross-sectional, observational design to describe patterns of mental health screening in pediatric primary care for children with ASD. Data were extracted from the larger implementation ATTAIN pilot (Stadnick et al., in press).

Setting

Full details about the ATTAIN pilot study procedures are described in Stadnick et al., in press. In brief, the two participating healthcare organizations were: 1) the largest network of pediatric primary care practices serving families in two Southern California counties and 2) a large integrated healthcare system providing primary and specialty care in seven counties in Southern California. Both healthcare organizations accept public and private insurance for primary care services. Clinical, administrative and executive leadership recommended six primary care clinics (three from each organization) to invite for participation. These clinics were selected based on geographic variation and patient composition to facilitate regional representation of families served. No selected clinic had an existing integrated *mental health care* model for pediatric patients, generally, or for special clinical populations including children with ASD. All six clinics agreed to participate. Providers were then recruited within those six clinics.

Procedures

A one-hour recruitment and training workshop was conducted by the research team at each of the six clinics between November and December 2019. Following the training, PCPs were offered printed and electronic training and research materials and had the option to enroll in the study. Enrolled PCPs were asked to use ATTAIN with five patients who met the inclusion criteria over the 4-month pilot period. The ATTAIN pilot was paused for 10 weeks in response to the March 19th, 2020 California COVID-19 stay-at-home order due to organizational changes at the participating clinics. The pilot was resumed for one month in June 2020 so that each clinic could contribute four months of screening data.

Inclusion criteria for children were: 1) ages 4–16 years old at time of pediatric visit, 2) documented ASD diagnosis, 3) caregiver spoke English or Spanish, 4) had an in-person well-child appointment during the pilot period. After identifying an eligible child, the caregiver was administered the PSC-17 either through the patient portal or on paper in their

preferred language. The completed PSC-17 was either scored automatically in the electronic health record or manually by the primary care team.

At the pilot study end, deidentified patient demographics and PSC-17 data were obtained from participating clinics. Due to patient health data exchange policies, data from Organization 2 were provided in aggregate form rather than at the individual-level so it was not possible to directly compare quantitative patterns between organizations. All procedures including informed consent procedures were approved by the Institutional Review Boards at the University of California San Diego and partner institutions.

Participants

A total of 29 PCPs from Organization 1 (n=14) and Organization 2 (n=15) enrolled in the study. The majority (59%) reported that they had worked at their organization as a PCP for five or more years (n=17). Most (90%) were physicians and 10% were nurse practitioners or physician assistants. PCPs self-reported as 35% (n=10) males, 66% (n=19) females, and 28% (n=8) Hispanic/Latino.

Measures

Pediatric Symptom Checklist-17.—The PSC-17 is a 17-item caregiver-report instrument to assess children’s psychosocial functioning. It has been validated in large, representative national pediatric outpatient samples, confirming its utility as a screening tool in pediatric settings (Murphy et al., 2016). The PSC-17 yields a Total Score, Internalizing Subscale, Externalizing Subscale and Attention Subscale. Caregivers were asked to indicate the frequency of each item ranging from “never” (0) to “often” (2). A Total Score 15 indicates a need for additional evaluation and support from a qualified mental health professional. The clinical thresholds for the other three subscales are: 7 or above for Externalizing or Attention and 5 or above for Internalizing. The PSC-17 was administered via patient portal in Organization 1 and via paper in Organization 2.

Electronic health records.—Demographic and service data for eligible patients were abstracted from electronic health records by staff in participating organizations. The following data were abstracted: child age, child ethnicity, confirmation of an ASD diagnosis, date of well-child appointment, PSC-17 scores, mental health referral documentation, status of mental health appointment, and free-text notes from the well-child visit related to the PSC-17 or mental health referral.

Data Analysis

Due to the data use agreements established with participating organizations, individual-level data were not available for comparison *between* organizations. Descriptive statistics and screening patterns are reported by each organization. Differences in demographic and clinical characteristics were examined *within* each organization using chi-square analyses for bivariate or proportional outcomes and one-way analyses of variance (ANOVA) for continuous variables.

Community Involvement

Community pediatric providers, organizational leaders, and caregivers of children with ASD were involved in the development of ATTAIN and its implementation.

Results

Eligible Patients

A total of 81 patients were eligible from Organization 1 and 85 patients were eligible from Organization 2. Eligible patients included those who had an existing ASD diagnosis listed in their medical record, were 4–16 years old at the time of their scheduled well-child appointment, and completed a well-child appointment during the study period. In Organization 1, eligible patients were an average age of 9.31 years ($SD = 3.54$) and 8.00 years ($SD = 3.94$) at Organization 2. Eligible patients were primarily male (Organization 1: 85%, Organization 2: 81%) and approximately half were Latino/Hispanic (Organization 1: 59%, Organization 2: 47%). Refer to Table 1 for demographic characteristics of eligible and screened patients.

Screened Patients

There were no significant differences in child demographics (age, biological sex or ethnicity) between patients screened and not screened within either organization. While both organizations had similar screening rates (Organization 1: 53%; Organization 2: 55%), case positivity (PSC-17 Total Score ≥ 15) was 47% in Organization 1 and 36% in Organization 2. For positive cases in Organization 1, PSC-17 subscale scores were highest on the Attention Subscale ($M=8.15$, $SD=1.31$), followed by the Externalizing ($M=7.55$, $SD=3.05$) and the Internalizing Subscales ($M=4.75$, $SD=2.73$). For Organization 2, subscale scores were highest on the Externalizing Subscale ($M=7.24$, $SD=2.02$), followed by the Attention ($M=7.12$, $SD = 1.65$) and the Internalizing Subscales ($M=3.88$, $SD=2.45$). One-way ANOVAs revealed that children with positive screens (Total Scores ≥ 15) had significantly higher Total and sub-scale PSC-17 scores compared to children with negative screens (Total Scores < 15) (all $ps < .001$). Refer to Table 2 for PSC-17 scores of screened patients.

Patients Referred to Mental Health Services Following Screening

Children did not differ in their demographic characteristics between those who were referred compared to those who were not referred within either organization. For Organization 1, 45% ($n=9$) were referred by their PCP to community mental health services. An internal referral was made to the organization's Call Center to provide support to the family in scheduling a mental health appointment for the referred child. Of those who were referred, 100% ($n=9$) were contacted by the organization's Call Center for scheduling support. The disposition from these outreach support calls were: unable to reach the family after four attempts (36%), family was already connected to mental health services (9%), or the family indicated that no further contact was needed (55%). For Organization 2, 47% ($n=8$) were referred by their PCP to mental health services within their organization's Psychiatry department. Of those who were referred, 100% ($n=8$) scheduled a Psychiatry

intake appointment and 63% (n=5) attended the appointment. There were no significant differences in age, sex, ethnicity, or PSC-17 scores between children referred, not referred/scheduled, or who completed an appointment.

Discussion

This study is one of the first to report mental health screening efforts in pediatric primary care focused on school-age children with autism. From our sample of six pediatric primary care clinics within two healthcare organizations, PSC-17 screening rates ranged from 53–55% and case positivity (i.e., clinically elevated PSC-17 screens) ranged from 36–47%. Screening results indicated that children in our sample had elevated scores on the Attention and Externalizing but not Internalizing subscales of the PSC-17. The high positive screen rate and the pattern of mental health need types are consistent with research reporting high rates of co-occurring mental health conditions for children with autism and the common co-occurrence of challenging behaviors, which includes both attention and externalizing symptoms, for these youth (Brookman-Frazer et al., 2018; Stadnick et al., 2020).

Following screening, approximately half (45–47%) of youth with positive PSC-17 screens had a documented referral to mental health services initiated by their PCP. The referral rate may be explained by several factors. Providers were encouraged to discuss mental health options with families whose children screened positive on the PSC-17. Specifically, providers were trained to inquire whether the family was already receiving mental health services and to discuss the difference between mental health services and other services that address healthcare needs of children with autism (e.g., applied behavior analysis, speech therapy, occupational therapy). If the family was already connected to mental health services or declined a referral, providers were encouraged to document the non-referral decision. Ultimately, both providers and families used their clinical or personal judgment to decide about initiating or acting upon a mental health referral.

For referred youth, 100% were subsequently connected to support staff outside of the primary care department to facilitate scheduling of a child's mental health appointment. There was variability in the rates of children who were referred for mental health services based on their PSC-17 screening result and who subsequently attended their appointment. There were no differences in patient demographics, most notably ethnicity, between those screened and not screened, and those who had positive screens and those referred to mental health care. It is encouraging albeit somewhat unexpected that screening and referral disparities were not noted in this youth. Participating clinics were selected to capture different geographic regions of Southern California, including higher proportions of ethnic minority, primarily Latino, families. The PSC-17 was also available in both Spanish and English and providers were encouraged to administer the screener in the caregivers' preferred language.

It was beyond the scope of this study to directly compare outcomes between participating organizations. However, findings suggest common areas of the screening, referral, and general implementation process that could be considered for future refinement. The most prominent area for refinement from this study appears to be in the post-screening, mental

health referral and care linkage phase. Findings indicated that only 45–47% of youth with positive PSC-17 screens had a documented mental health referral by their pediatrician; however, all those referred were contacted to support mental health care appointment scheduling. Provider clinical judgment and family preference likely impacted this referral rate yet there is growing acknowledgment of the high mental health care access needs for individuals with autism across the lifespan (Maddox, Dickson, Stadnick, Mandell, & Brookman-Fraze, 2021). Undoubtedly, refinement within this phase may suggest a collaborative, systems-approach with organizational leadership, providers, and caregivers to safeguard against workflow and workforce constraints that are common in primary care settings (Privett & Guerrier, 2021).

In addition, it is possible that mental health screening and referral patterns may have been altered during the pilot period, which spanned the early months of the COVID-19 pandemic. It was not possible to examine the monthly changes in patterns due to the aggregated nature of the pilot data. However, we acknowledge the potential impacts of the pandemic. Emergent literature has reported the elevated mental health needs of children and adolescents since the onset of the pandemic (Creswell et al., 2021; Ravens-Sieberer et al., 2021). In addition, recent reports have highlighted the “digital divide” since the COVID-19 pandemic with respect to disproportionate access to telehealth, including primary care services for families from economically marginalized backgrounds (Chang et al., 2021).

Several limitations should be noted. First, data were unable to be compared at the individual-level across organizations. This resulted in small sample sizes especially within latter parts of the screening and referral components of the process. Related to the sample size limitation is the impact of the COVID-19 pandemic. This study took place during the initial period of the COVID-19 pandemic, which significantly reduced the volume of well-child appointments and eligible patient pool for this study. While the sample sizes were small, a strength to balance the small sample sizes was that the ethnic diversity of patients was representative of children identified as Hispanic/Latino within San Diego County census data (46%) (All Data: San Diego County, 2021). A final limitation is that ATTAIN relies on the caregiver-report version of the PSC-17 to assess child mental health needs. Reliance on caregiver report may have resulted in over or under report of mental health needs. For example, our findings indicated that children in our sample did not evidence elevations on the Internalizing subscale of the PSC-17. While challenging behaviors are the most common mental health need in school-age children with ASD (Brookman-Fraze et al., 2018; Stadnick et al., 2020), there is potential that caregivers under-reported internalizing symptoms because they can be difficult to recognize.

While screening has important prevention potential, screening is not without its costs to the health care system, providers and families and thus, the benefits must outweigh the costs (Hickey et al., 2020). Related, a future direction of this research is to understand optimal timing of assessing for mental health needs in a family’s developmental experience with autism. For families who have newly received an autism diagnosis, immediate screening for co-occurring mental health needs may be overwhelming and potentially reduce care access or engagement. For other families, mental health needs assessment may be well-received and critical to determine appropriate course of treatment. Findings from this study indicated

that not all eligible children with autism were screened. Although it was beyond this study's scope to examine providers' decision-making about patient screening selection, pursuing this topic may contribute to determining optimal timing for mental health needs assessment.

This study offers an initial proof-of-concept for the feasibility of implementing a brief, comprehensive mental health screening tool by pediatric PCPs to identify co-occurring mental health needs for children with autism. Our next steps are to convene a series of iterative debrief meetings with organizational leaders, providers, and caregivers to determine refinements needed for potential scaling of mental health screening efforts across pediatric clinics. In addition, the infrastructure developed and described in this study will be leveraged to support refining and implementing a family navigation intervention to optimize personalized mental health care linkage for school-age children with autism at risk for mental health needs in a newly funded stepped-wedge implementation trial (R34 MH120190).

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Table 1.

Demographic Characteristics of Patients Eligible and Screened

Organization 1					
Patient Demographics	Total Eligible (N = 81)	Not Screened (N = 38)	Total Screened (N = 43)	Screened - (N = 23)	Screened + (N = 20)
Age <i>M(SD)</i>	9.31 (3.54)	9.34 (3.79)	9.28 (3.35)	9.74 (3.05)	8.75 (3.67)
Biological Sex n(%)					
Male	69 (85.2%)	32 (84.2%)	36 (83.7%)	20 (87.0%)	17 (85.0%)
Female	11 (13.6%)	5 (13.2%)	6 (14%)	3 (13.0%)	3 (15.0%)
Ethnicity n(%)					
Latino/Hispanic	48 (59.3%)	21 (55.3%)	27 (62.8%)	14 (60.9%)	13 (65.0%)
Non-Latino/Hispanic	32 (39.5%)	17 (44.7%)	15 (34.9%)	8 (34.8%)	7 (35.0%)
Organization 2					
Patient Demographics	Total Eligible (N = 85)	Not Screened (N = 38)	Total Screened (N = 47)	Screened - (N = 30)	Screened + (N = 17)
Age <i>M(SD)</i>	8.00 (3.94)	7.71 (3.82)	8.20 (4.10)	8.03 (4.05)	8.59 (4.20)
Biological Sex n(%)					
Male	69 (81.2%)	31 (81.6%)	37 (80.2%)	23 (76.7%)	15 (88.2%)
Female	16 (18.8%)	7 (18.4%)	9 (19.1%)	7 (23.3%)	2 (11.8%)
Ethnicity n(%)					
Latino/Hispanic	40 (47.1%)	15 (39.5%)	25 (53.2%)	19 (63.3%)	6 (35.3%)
Non-Latino/Hispanic	39(45.9%)	21 (55.26%)	18 (38.3%)	10 (33.3%)	8 (47.1%)

Note. No significant differences between children not screened and screened for age, biological sex, or ethnicity for either organization. Organization 1 had one missing data point for biological sex and one missing data point for ethnicity; Organization 2 had 6 missing data points for ethnicity.

Table 2.

PSC-17 Scores of Patients Screened

Organization 1				
PSC-17 Score <i>M(SD)</i>	Total Screened (N = 43)	Screened – (N = 23)	Screened + (N = 20)	
Total (cutoff = 15)	14.47 (7.18)	9.26 (3.82)	20.45 (5.15)	$F(1, 41) = 66.69, p < .001$
Internalizing (cutoff = 5)	3.16 (2.82)	1.78 (2.11)	4.75 (2.73)	$F(1, 41) = 16.12, p < .001$
Externalizing (cutoff = 7)	5.16 (3.35)	3.09 (1.92)	7.55 (3.05)	$F(1, 41) = 33.76, p < .001$
Attention (cutoff = 7)	6.14 (2.67)	4.39 (2.29)	8.15 (1.31)	$F(1, 41) = 41.86, p < .001$
Organization 2				
PSC-17 Score <i>M(SD)</i>	Total Screened (N = 47)	Screened – (N = 30)	Screened + (N = 17)	
Total (cutoff = 15)	11.53 (6.29)	7.73 (3.67)	18.24 (3.82)	$F(1, 45) = 86.46, p < .001$
Internalizing (cutoff = 5)	2.04 (2.27)	1.00 (1.34)	3.88 (2.45)	$F(1, 45) = 27.45, p < .001$
Externalizing (cutoff = 7)	4.45 (2.84)	2.87 (1.83)	7.24 (2.02)	$F(1, 45) = 57.34, p < .001$
Attention (cutoff = 7)	5.04 (2.57)	3.87 (2.24)	7.12 (1.65)	$F(1, 45) = 27.27, p < .001$

Note. One-way ANOVAs indicated significantly higher Total and sub-scale scores on the PSC-17 for children with positive PSC-17 screens (Total Scores ≥ 15) compared to children with negative PSC-17 screens (Total Scores < 15).