Child Welfare and Autism: A Descriptive Study at an Integrated Pediatric Primary Care Center

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Introduction

Autism spectrum disorder is a lifelong, developmental disorder that affects communication and behavior to varying extents.[1,2] In 2013, the American Psychiatric Association released new DSM-V criteria which revised the autism definition. The new definition merges four diagnoses—autistic disorder, Asperger's syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS)—into a single diagnosis of autism spectrum disorder. Children with autism have a 2.4 times higher risk of entering the foster care system than children without autism[3]. The cause of this discrepancy is unknown but possible causes include insufficient resources, ignorance to specialized needs, and inadequate experience raising a child with autism which contribute to neglect, abuse, and/or involvement of child welfare services (i.e. foster care).[4] In addition to being more likely to enter foster care, children with autism spend 1.6 times longer in out-of-home care than do foster children without autism[5]. This study will examine the prevalence, percentages, and frequencies of behavioral and medical conditions of children in this population using visit data compiled from an integrated primary care center.

Abstract

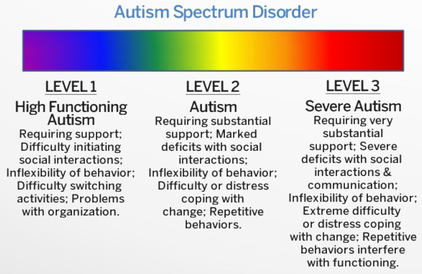
Estimates suggest Autism Spectrum Disorder (ASD) affects up to 10 percent of children in the child welfare population. Much of the relevant literature has focused on the susceptibility of children with ASD to entering the child welfare system. Missing from the literature is information on children with an ASD diagnosis once they have entered the child welfare system. To address this gap, a retrospective chart chart review was conducted on patients seen at two integrated pediatric primary care clinics exclusively serving children involved in the child welfare system. After identifying children with an ASD diagnosis, frequencies and descriptive statistics were conducted to describe the sample. Results were significant for 76% of children (N=55) having comorbid chronic and behavioral conditions, 62% of children requiring at least 1 psychotropic medication, 62% of children having at least 1 chronic condition (excluding behavioral), and 36% of children having specialized therapy services ordered/received.

Description of Study

Using Epic, electronic medical records were reviewed for ICD-10 codes specific for ASD diagnoses (F84.0, F84.3, F84.5, and F84.9) between January 2017 and December 2018. Fifty five patients were identified to have ASD diagnoses within the duration of the study. ICD codes were collected across all visits within the time period at the Reese-Jones Foster Care Centers at Dallas and Plano, TX. Visit types included new patient visits, well child checks, psychology, and integrated patient encounters. Parameters collected for each patient included demographic data, behavioral issues, behavioral health diagnoses, chronic condition diagnoses, psychotropic medication prescriptions, and ordered therapeutic services (PT, ST, OT).

Table 1: Demographic Data and Exposure Counts (N=55)

Demographics	Aged 0-17 *n (%)*	Aged 3-5 *n (%)*	Aged 6-11 *n (%)*	Aged 12+ *n (%)*
Race				
Black/African American	19 (34.5%)	5 (9.1%)	9 (16.4%)	5 (9.1%)
White/Caucasian	28 (50.9%)	8 (14.5%)	11 (20.0%)	9 (16.4%)
Other	3 (5.5%)	2 (3.6%)	0 (0.0%)	1 (1.8%)
Unknown	5 (9.1%)	2 (3.6%)	2 (3.6%)	1 (1.8%)
Ethnicity				
Hispanic/Latinx	7 (12.7%)	3 (5.5%)	2 (3.6%)	2 (3.6%)
Non-Hispanic/Latinx	44 (80.0%)	11 (20.0%)	19 (34.5%)	14 (25.5%)
Unknown	4 (7.3%)	2 (3.6%)	1 (1.8%)	1 (1.8%)
Gender				
Male	45 (81.8%)	16 (29.1%)	14 (25.5%)	15 (27.3%)
Female	10 (18.2%)	0 (0.0%)	9 (16.4%)	1 (1.8%)
Placement Type				
Foster Care	48 (87.3%)	15 (27.3%)	17 (30.9%)	16 (29.1%)
Kinship Care	5 (9.1%)	4 (7.3%)	1 (1.8%)	0 (0.0%)
CPS	2 (3.6%)	0 (0.0%)	1 (1.8%)	1 (1.8%)
Exposures				
Physical Abuse	10 (18.2%)	3 (5.5%)	3 (5.5%)	4 (7.3%)
Sexual Abuse	3 (5.5%)	0 (0.0%)	2 (3.6%)	1 (1.8%)
Neglect	48 (87.3%)	15 (27.3%)	20 (36.4%)	13 (23.6%)
Domestic Violence	3 (5.5%)	2 (3.6%)	1 (1.8%)	0 (0.0%)
Other	6 (10.9%)	0 (0.0%)	4 (7.3%)	2 (3.6%)
Exposure Count				
≥ 1 Exposure	54 (98.2%)	16 (29.1%)	22 (40.0%)	16 (29.1%)
≥ 2 Exposure	15 (27.3%)	6 (10.9%)	5 (9.1%)	4 (7.3%)



Results

A total of 55 children (N=55) were identified with ICD codes for ASD diagnoses over the duration of the study. In regards to demographic data (Table 1), approximately 51% of the children were identified as Caucasian/white and 35% were Black/African-American. The gender distribution was skewed with 82% of the children identified as biologically male and 18% as biologically female. Placement type was predominantly foster homes at a large margin of 87%. Kinship placement followed at 9.1%. In terms of exposure history, patients were reported multiple types of exposures across the age categories. 98% of the patients reported at least 1 type of exposure while 27% reported at least 2 types of exposures. 87% reported some form of neglect, 18% reported physical abuse, 6% reported sexual or domestic abuse, and 11% reported some other type of exposure. For behavioral and clinical data (Table 2), behavioral comorbidities were excluded from chronic conditions counts by omitting "F" categories of ICD-10 codes. 62% of the patients displayed at least 1 chronic medical diagnosis while 51% displayed at least 2 diagnoses. 62% of the patients were diagnosed with at least 1 behavioral health diagnosis while 38.2% were diagnosed with at least 2 behavioral health diagnoses. Combining these 2 categories, 76% of the patients had co-occurring chronic and behavioral health diagnoses. 38% of patients were not prescribed any psychotropic medications while 62% were prescribed at least 1 psychotropic medication. 46% of the patients displayed a behavioral issue or high-risk behavior (including sexual behaviors, aggression, or tantrums). 36% of the patients had therapy services (PT, ST, or OT) receiving or ordered per chart review.

Table 2: Measured Behavioral and Clinical Parameters (N=55)

Clinical and Behavioral Data	Aged 0-17 *n (%)*	Aged 3-5 *n (%)*	Aged 6-11 *n (%)*	Aged 12+ *n (%)*
Chronic Condition Count				
≥ 1 chronic condition	34 (61.8%)	7 (12.7%)	12 (21.8%)	15 (27.3%)
≥ 2 chronic conditions	28 (50.9%)	7 (12.7%)	10 (18.2%)	11 (20.0%)
Mental Health Diagnosis Count				
Children with ≥ 1 mental health diagnosis	34 (61.8%)	10 (18.2%)	13 (23.6%)	11 (20.0%)
Children with ≥ 2 mental health diagnoses	21 (38.2%)	7 (12.7%)	7 (12.7%)	7 (12.7%)
Co-Occurring Chronic Condition and Mental Health Diagnosis	42 (76.4%)	9 (16.4%)	18 (32.7%)	15 (27.3%)
Psychotropic Medications				
No psychotropic medication	21 (38.2%)	7 (12.7%)	8 (14.5%)	6 (10.9%)
≥ 1 psychotropic medications	34 (61.8%)	9 (16.4%)	14 (25.5%)	11 (20.0%)
Behaviors & High-Risk Behaviors	25 (45.5%)	9 (16.4%)	11 (20.0%)	5 (9.1%)
Therapy Services (Receiving or Referred)	20 (36.4%)	10 (18.2%)	8 (14.5%)	2 (3.6%)

*Chronic condition diagnoses excludes all mental health/behavioral diagnoses

Conclusions

The goal of this descriptive study is to identify trends, disparities, risk factors, and areas of need for autistic children in the child welfare system. This is still an area of research that is severely lacking in publications for a very vulnerable population. The main limitation of this study is the small sample size used. Despite the small size, there were very high percentages of children with comorbid chronic and mental health diagnoses as well as receiving psychotropic medications and/or therapy services. This highlights significant area of need that autistic children entering foster care may not receive adequate management if they don't receive care at a specialized center. This study combined patients from 2 primary integrated care centers, but future studies can look into performing a similar analysis across multiple hospitals. Another suggestion for future studies would involve comparing the frequencies of these risk factors and comorbidities with children with ASD who are not in the child welfare system.

References

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