

Prevalence of Neurodevelopmental Disorders Among Low-Income African Americans at a Clinic on Chicago's South Side

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Objective: This study examined the point prevalence of neurodevelopmental disorders among predominantly low-income, African-American psychiatric patients at Jackson Park Hospital's Family Medicine Clinic on Chicago's South Side.

Methods: Using active case ascertainment methodology, the authors assessed the records of 611 psychiatric patients visiting the clinic between May 23, 2013, and January 14, 2014, to identify those with *DSM-5* neurodevelopmental disorders.

Results: A total of 297 patients (49%) met criteria for a neurodevelopmental disorder during childhood. Moreover, 237 (39%) had clinical profiles consistent with neurobehavioral

disorder associated with prenatal alcohol exposure, and 53 (9%) had other neurodevelopmental disorders. The authors disagreed on the specific type of neurodevelopmental disorder of seven (1% of 611) of the 297 patients with neurodevelopmental disorders.

Conclusions: A high prevalence of neurodevelopmental disorders was found among low-income predominantly African-American psychiatric patients on Chicago's South Side. If replicated, these findings should bring about substantial changes in medical practice with African-American patients.

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A 1979 study of low-income African-American children revealed high prevalence rates of intellectual disability (1). The study indicated that children who were referred for special education services had intellectual disability, speech and language difficulties, hyperactivity, high excitability, high distractibility with poor attention span, and poor frustration tolerance, leading to poor impulse and affect control and resulting in violent or explosive behavior (1). The children had varying levels of disturbances in memory, judgment, and neurological signs (1).

In retrospect, this population had what the *DSM-5* currently considers to be neurodevelopmental disorders. This category of psychiatric illnesses begins during the developmental period. *DSM-5* divides neurodevelopmental disorders into six categories: intellectual disability, communication disorders, autism spectrum disorders, attention-deficit hyperactivity disorder (ADHD), specific learning disorders, and neurodevelopmental motor disorders (2). *DSM-5* Section III, Emerging Measures and Models Under Conditions for Further Study, proposes criteria for neurobehavioral disorder associated with prenatal alcohol exposure (2). This disorder is aligned with medical concepts of fetal alcohol syndrome (3), the most severe outcome of fetal alcohol exposure, and fetal alcohol spectrum disorders, which have less severe outcomes (4). Fetal alcohol spectrum disorders affect as many as 2% to

5% of young children in the United States (5). Neurobehavioral disorder associated with prenatal alcohol exposure is estimated to be the single largest preventable cause of intellectual disability (5). Overall, fetal alcohol exposure is the leading cause of speech and language disorders, ADHD, specific learning disorders, and mild intellectual disability, which are often responsible for affect dysregulation leading to disruptive behaviors and even incarceration (6).

There is a dearth of research on people of color (7). Accordingly, findings from basic empirical research on people of color fill an essential knowledge gap (8). Native Americans and Alaskan Eskimo-Inuits have the highest reported rates of fetal alcohol spectrum disorders, and African Americans are next in line (9). However, in our clinical experience with African-American patients, we often see vestiges of the physical signs of fetal alcohol syndrome. Considering social determinants of health, specifically the plethora of liquor stores in low-income, African-American communities, and the new *DSM-5* proposed criteria for neurobehavioral disorder associated with prenatal alcohol exposure (2), we decided to ascertain the prevalence of neurodevelopmental disorders with a focus on this potential new category among psychiatric patients attending Jackson Park Hospital's Family Medicine Clinic.

METHODS

We used active case ascertainment methodology (5) to determine the prevalence of *DSM-5* neurodevelopmental disorders among patients attending Jackson Park Hospital's Family Medicine Clinic. To improve scientific rigor and prevent confirmatory bias, questions were developed from *DSM-5* to identify neurobehavioral disorder associated with prenatal alcohol exposure (2). [These questions are listed in an online supplement to this report.] Physical signs of fetal alcohol exposure were also assessed for all patients. Using these guidelines, the first author conducted psychiatric evaluations for 611 psychiatric patients seeking services at the clinic from May 23, 2013, to January 15, 2014. Later, we removed all identifying information from these patients' electronic medical records. Each author then used a checklist to score each patient's record to determine whether the patient met *DSM-5* criteria for neurodevelopmental disorder. Patients meeting criteria were divided into those who met criteria for a neurobehavioral disorder associated with prenatal alcohol exposure, those who met criteria for a neurobehavioral disorder associated with prenatal alcohol exposure but for whom information was missing on the mother's drinking history when she was pregnant, and those who met criteria for a neurodevelopmental disorder not associated with prenatal exposure to alcohol.

The cardinal features of a neurodevelopmental disorder history were easily obtained in a short time. These patients endorsed a childhood history of special education or learning disorders; being teased by other children about being "slow"; hyperactivity; problems with speech and language; poor impulse control and affect regulation; poor memory; and not doing well in life in the areas of social, academic, and occupational functioning. Furthermore, these problems persisted into adulthood. Even though the vestiges of fetal alcohol exposure facies had receded over time, many patients still manifested these facies. There were also occasional physical signs of fetal alcohol exposure, for example, congenital heart murmur and strabismus.

Many of the mothers of patients with neurodevelopmental disorders were still intimately involved in their children's lives. When possible, a history of maternal drinking during pregnancy was obtained in a respectful manner. The mother was first asked how old she was when the patient was born, when she knew that she was pregnant (at one to two months was the usual answer), what her lifestyle was before she knew she was pregnant (for example, whether she partied often), and whether she may have been drinking when she was pregnant with the patient.

Because patient-identifying information was removed, there was no risk to the patients. Therefore, Jackson Park Hospital's Institutional Review Board granted us a research waiver. Data were analyzed with SPSS, version 21.

RESULTS

We reviewed 611 charts for 590 adults and 21 youths (≤ 18 years). Among adult patients, more than 96% ($N=566$) were

TABLE 1. Patients who underwent psychiatric assessments at Jackson Park Hospital's Family Medicine Clinic to identify neurodevelopmental disorders

| Disorder | Adults (N=590) | | Children (N=21) | |
|---|-------------------|----|--------------------|----|
| | N | % | N | % |
| Neurobehavioral disorder associated with prenatal alcohol exposure | 224 | 38 | 12 | 57 |
| Met <i>DSM-5</i> criteria | 87 | 14 | 10 | 48 |
| Met <i>DSM-5</i> criteria and near certainty that mother drank during pregnancy | 40 | 7 | 2 | <1 |
| Met <i>DSM-5</i> criteria but no information about maternal drinking history | 97 | 16 | | |
| Other types of neurodevelopmental disorders | 45 | 8 | 8 | 38 |
| Authors disagreed about the type of neurodevelopmental disorder | 7 | 1 | | |
| Total with a neurodevelopmental disorder | 276 | 47 | 20 | 95 |

African American, 247 (39%) were male, 364 (61%) were female, and the average age was 45 (range, 19 to 78). Among the youths, all were African American, 16 (76%) were male, five (24%) were female, and the average age was 13 (range, four to 18). Ninety-eight percent ($N=599$) of patients in the sample resided in one of the three zip codes (60617, 60619, and 60619) on Chicago's South Side (Avalon Park, Burnside, Chatham, Greater Grand Crossing, and South Shore communities). About 143,000 people live in these communities, and their median household income is \$33,809. A total of 578 patients (95%) were on public assistance for medical care, and 32 (5%) had private insurance; payment status information was missing for one patient (<1%).

Table 1 presents diagnostic findings. Among the 590 adults, 276 met criteria for a neurodevelopmental disorder. Moreover, 224 adults had a clinical profile consistent with neurobehavioral disorder associated with prenatal alcohol exposure. Forty-five adults (8%) had standard *DSM-5* neurodevelopmental disorders: intellectual disability, 18 (3%); autism spectrum disorder, five (1%); ADHD, four (<1%); specific learning disorders, eight (1%); other neurodevelopmental disorders, five with traumatic brain injury (<1%), two with meningitis (<1%), two with hypoxia at birth (<1%), and one with seizures, (<1%). Our interrater reliability was 98%. We disagreed about seven patients about whether their neurodevelopmental disorder was associated with prenatal alcohol exposure (1% of the 590 adults), and to be conservative, these patients were not counted as having neurobehavioral disorder associated with prenatal alcohol exposure.

Of the 21 youths, all but one, who had an anxiety disorder (posttraumatic stress disorder), had neurodevelopmental disorders. Ten met strict criteria for neurobehavioral disorder associated with prenatal alcohol exposure; two met criteria for neurobehavioral disorder associated with prenatal alcohol exposure, but confirmed information was lacking about the

mother's drinking during pregnancy (collaterals were almost certain that mother was drinking); and eight had other neurodevelopmental disorders (Table 1).

DISCUSSION

Our results suggest that neurodevelopmental disorders, especially those associated with prenatal alcohol exposure, are a serious problem in the lower-income, African-American community on Chicago's South Side. Signs of prenatal alcohol exposure were easily identified by using standard screening questions developed from *DSM-5*. Frequently, the available mothers of children or adult children with neurodevelopmental disorders were able to give a history that indicated the etiology of the disorder. Most reported being young mothers (under age 26) who did not know they were pregnant until after the first or second or month and who drank during this period. Most reported that they stopped drinking when they realized they were pregnant.

Even though this study focused on a large convenience sample, it found that neurobehavioral disorder associated with prenatal alcohol exposure was commonplace—388 per 1,000 population. Multiple previous studies that used active case ascertainment methodology with Native American populations ages 0–21 found rates of fetal alcohol spectrum disorder between two and 120 per 1,000 population (5). The variation in these prevalence studies results from the use of different criteria, methods, and sampling techniques; most studies investigated the disorder among infants and youths. Our study is unique because it focused primarily on an adult primary care population and used psychiatric criteria to identify these disorders.

The findings raise the issue of misdiagnosis of neurodevelopmental disorders. Many of the patients who had neurobehavioral disorder associated with prenatal alcohol exposure had received previous diagnoses of schizophrenia, bipolar disorder, and depression. We suspect that they were given a schizophrenia diagnosis because they had impaired neurocognitive functioning and concrete thinking, which gave the appearance of a thought disorder and vague psychotic symptoms. However, they did not have the deterioration in psychosocial functioning that is characteristic of schizophrenia, because this set of skills had never been fully developed. In addition, they were highly interpersonal, albeit in a naïve, childlike manner. It is also interesting that 50% of the patients with neurobehavioral disorder associated with prenatal alcohol exposure developed psychotic symptoms in their 30s and 40s that were not related to schizophrenia. However, strictly speaking, their psychosis was not characteristic of schizophrenia, bipolar disorder, or major depression. Their impaired self-regulation (characterized by poor attention and impulse control) was, despite its short and intermittent course, interpreted as bipolar disorder. We also suspect that the patients were diagnosed as having depression because of their unhappiness about their chronic inability to improve their social, academic, or occupational functioning. Many patients with

neurodevelopmental disorders were sexually and physically abused as children and adults, and many had histories of substance abuse, violence as adults, and incarceration. Several had experienced traumatic brain injury as children or adults that seemed to be attributable to a lack of recognition of risky behaviors and to getting into fights as adults.

The recent research on neurobehavioral disorder associated with prenatal alcohol exposure makes acting on these findings imperative (10,11). The first priority in the well-known issue of universal prevention and efforts to keep women from drinking while pregnant (6). Second are the lesser-known selected prevention interventions for women who may have been drinking before they knew they were pregnant (6). Research has shown that choline plays a major role in the development of fetal alcohol spectrum disorders (10). For example, giving choline in the second and third trimesters to pregnant rats that were fed alcohol in their first trimester mitigated the deleterious effects of fetal alcohol exposure (11). Screening pregnant females for “drinking before they knew they were pregnant” and giving them choline is an attractive prevention strategy. This is especially true for women entering corrections facilities because 6% to 10% of incarcerated women are pregnant (12). Finally, with regard to “indicated prevention or postvention,” research shows that giving choline to infants is a postdelivery strategy that can ameliorate some of the sequelae experienced by both animals and children with neurobehavioral disorder associated with prenatal alcohol exposure (13).

The high prevalence of neurobehavioral disorder associated with prenatal alcohol exposure among the predominantly low-income, African-American children presenting for psychiatric services in a family medicine clinic strongly suggests the need for screening African-American children in low-income areas. Screening is important considering the possible postnatal treatment for these disorders (13).

A shortcoming of this study is it may not be generalizable to other African-American populations because the sample was not representative. Patients in a primary care setting may differ from those in a community mental health center. However, we maintain that the circumstances creating this hidden epidemic are ubiquitous—liquor stores are a prominent feature of African-American ghettos. Accordingly, this study must be replicated on a larger scale. Another limitation is the lack of an objective standardized diagnostic test for fetal alcohol syndrome and spectrum disorders. However, we hope that the *DSM-5* proposed diagnosis will permit accurate and reliable detection of this common clinical syndrome.

CONCLUSIONS

Neurodevelopmental disorders, especially neurobehavioral disorder associated with prenatal alcohol exposure, are a large, undetected problem in the low-income African-American community on Chicago's South Side. Clinicians need to become more adept at obtaining patients' historical information and identifying physical characteristics of neurodevelopmental

disorders, especially neurobehavioral disorder associated with prenatal alcohol exposure. Researchers need to replicate and extend these findings so that the significance of the problem is recognized and clinicians' awareness of it increases. If confirmed, these findings could drive major changes in the practices of obstetricians and gynecologists, family medicine and pediatric physicians, and psychiatrists.

Prevention is coming of age in psychiatry. Furthermore, the American Academy of Pediatrics, the Centers for Disease Control and Prevention, the Office of Juvenile Justice and Delinquency Prevention, and the National Institute of Child Health and Human Development are all working on this issue with mobile apps and public service announcements (14,15). As one older woman with neurobehavioral disorder associated with prenatal alcohol exposure put it, "I know I am slow and have emotional issues, but I want to be a success too." We have to do all we can to help her achieve her goal.

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