An Interdisciplinary Approach to Increasing Access to Care for Individuals with Fetal Alcohol Spectrum Disorders

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Abstract

Fetal alcohol spectrum disorders (FASD) have a prevalence of roughly 1 in 20, making it one of the most prevalent disorders in the United States (May et al., 2018). However, FASD has a diagnostic rate of less than 1%, resulting in late diagnosis, identification, and intervention (May, Baete, & Russo, 2014; May, Chambers, Kalberg, et al, 2018; Cleveland, Deere, Kyzer, & Smith, 2020). Only a handful of physicians regularly diagnose FASDs, even further decreasing access to care (Manning & Hoyme, 2007). In response, the Specialty Diagnostic Resource Center (SDRC) in Arkansas developed the following interdisciplinary approach to FASD diagnosis. Seventy-seven individuals ages four months to 37 years were evaluated for Other Specified Neurodevelopmental Disability: Neurodevelopmental Disability Associated with Prenatal Alcohol Exposure (ND-PAE) between April 2020 and February 2022; 54 individuals were diagnosed. Trends were identified for individuals given a ND-PAE diagnosis and analyzed, with Spearman-rho analysis conducted. As FASDs are widely underdiagnosed, an approach similar to SDRC may assist other interdisciplinary teams in efforts to increase access both to diagnosis and intervention.

Keywords: fetal alcohol spectrum disorders, FASD, interdisciplinary care, access to care

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Fetal alcohol spectrum disorders (FASD) is an umbrella term that encompasses a variety of disorders caused by prenatal alcohol exposure (Vaurio, Riley, & Mattson, 2008; Astley, Aylward, Olson, Kerns, Brooks, Coggins, … & Kraegel, 2009; Riley, Infante, & Warren, 2011; Paolozza, Rasmussen, Hanlon-Dearman, Nikkel, Andrew, McFarlane, … & Reynolds, 2014; Hoyme, Kalberg, …& May, 2016; Thorne & Coggins, 2016; Terband, Spruit, & Maassen, 2018). Diagnoses that fall under the FASD umbrella include: (a) Fetal Alcohol Syndrome (FAS); (2) Partial Fetal Alcohol Syndrome (pFAS); (3) Alcohol Related Birth Defects (ARBD); (4) Alcohol Related Neurodevelopmental Disorder (ARND); (5) Prenatal Alcohol Effects (PAE); (6) Fetal Alcohol Effects (FAE); (7) Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE; (8) and many others (Hoyme et al., 2016; Kable & Mukherjee, 2017). May and colleagues (2018) identified a prevalence of 1 in 20 first graders in the US. Although this category of disorders is almost twice as prevalent as autism spectrum disorder (APA, 2013), less than 1% of children that meet criteria for FASD are actually given a diagnosis (May et al., 2018). Underdiagnosis to this extent often results in a misinterpretation of the common behaviors and characteristics associated with brain damage caused by prenatal alcohol exposure (Rasmussen, Benz, Pei, Andrew, Schuller, Abele-Webster, Alton et al., 2010; McLaughlin, Thorne, Jirikowic, Waddington, Lee, & Astley Hemingway, 2019; Cleveland et al., 2020).

The level of impairment for the FASD diagnoses vary depending on several factors, including amount of alcohol exposure, timing of exposure, and epigenetics (Riley & McGee, 2005; Moore, Ward, … & Foroud, 2007; Astley et al., 2009, Mattson, Crocker, & Nguyen, 2011; Feldman, Jones, … & Chambers, 2012). Each disorder has some combination of

impairment in neurological structure, impairment in adaptive or educational functioning, cognition, and/or behavioral characteristics that have been impacted by prenatal alcohol exposure (Vaurio et al., 2008; Astley et al., 2009; Riley et al., 2011; Paolozza et al., 2014; Thorne & Coggins, 2016; Terband, et al., 2018). Although there is a spectrum of severity of symptoms associated with each FASD diagnosis, there are also some common behavioral and structural characteristics that have been identified in all FASD diagnoses (Astley et al., 2009; Cook, Green, Lilley, Anderson, Baldwin, Chudley, … & Mallon, 2016). Functional magnetic resonance imaging (fMRIs) indicates that, although damage from prenatal alcohol exposure can happen anywhere in the brain, it is commonly seen in the corpus callosum and in the frontal lobe (Astley et al., 2009; Paolozza et al., 2014). Damage to these areas can cause decreased cognitive and executive functioning skills, like problem solving, organizing, understanding cause and effect, and ability to attend (Paolozza et al., 2014; Petrenko & Alto, 2014; Thorne, 2017). The absence or dysfunction of these skills may impact many areas of a person's life, including their ability to adapt to and function in the environment, which can then lead to behavioral characteristics such as inappropriate outbursts, impulsivity, and irregular social interactions (Fahy, 2014; Popova, Lange, Burd, & Rehm, 2014).

Many individuals with FASD are misdiagnosed as having attention deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), oppositional defiant disorder (ODD), disruptive mood dysregularion disorder (DMDD) and many others (Malbin, 2002; Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011; Lange, Shield, Rehm, & Popova, 2013; Popova, Lange, Shield, Mihic, Chudley, Mukherjee, Bekmuradov, & Rehm, 2016; Craig, Margari, Legrottaglie, Giambattista, & Margari, 2016). Lack of FASD diagnosis has resulted in societal misunderstanding of these disorders and ultimately the lack of appropriate supports and interventions for people with FASD (Carmichael-Olson, Ohlemiller, O'Connor,

Brown, Morris, & Damus, 2009). Without an official diagnosis of an FASD, it may be difficult to understand these children and their deficits, which in turn may create more complication for practitioners in attempting to provide the best level of care (Carmichael-Olson, et al., 2009).

Access to FASD Diagnosis

Although the importance of getting an FASD diagnosis has been well documented (Vaurio et al., 2009; Riley, Infante, & Warren, 2011; Paolozza et al., 2014; Hoyme et al., 2016; Thorne & Coggins, 2016; Terband, Spruit, & Maassen, 2018; Cleveland, et al., 2020), resources for diagnosis and intervention services continue to be minimal across the United States (Lange et al., 2013; Papov, et al., 2016; Petrenko & Alto, 2017; May et al., 2018; Cleveland et al., 2020). Very few physicians specialize in developmental and behavioral pediatrics, much less specifically specializing in fetal alcohol spectrum disorder (Manning & Hoyme, 2007). Arkansas, like many other states, has very limited access to FASD diagnosis and care (Cleveland et al., 2020). The Specialty Diagnostic Resource Center (SDRC), Arkansas's only FASD-specific diagnostic clinic, has utilized an interdisciplinary approach to care for individuals suspected of FASD. By identifying trends in diagnosis and symptomology like those identified through SDRC, other interdisciplinary teams across the country may be able to increase access to care in their own states.

Method

Analysis of the data collected through SDRC was conducted under IRB #20-153 at the University of Central Arkansas. An interdisciplinary team consisting of a speech-language pathologist, social worker, genetic counselor, and nurse practitioner was utilized for each SDRC evaluation. This team members are also current or former faculty members of the

Arkansas Leadership Education in Neurodevelopmental Disabilities (AR LEND) grant-funded training program. Because the nature of the clinic is a training clinic, students from a variety of disciplines also participate in each evaluation.

Diagnostic Criteria for Other Specified Neurodevelopmental Disorders: ND-PAE

SDRC evaluated 77 individuals between April 2020 and February 2022 using the criteria for Other Specified Neurodevelopmental Disability: Neurodevelopmental Disability Associated with Prenatal Alcohol Exposure (ND-PAE) from the DSM-5 (APA, 2013; Kable & Mukherjee, 2017). Criteria for ND-PAE can be found in Table 1.

Table 1

DSM-5 Diagnostic Criteria for ND-PAE

Other Specified Neurodevelopmental Disorder: Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure - 315.8 (F88)

A. History of more than minimal levels of prenatal alcohol exposure
B. Neurocognitive Impairment (one or more of the following)
    1. Global intellectual impairment
    2. Impairment in executive functioning
    3. Impairment in learning
    4. Impairment in memory
    5. Impairment in visual spatial reasoning
C. Impairment in self-regulation (one or more of the following)
    1. Impairment in mood or behavioral regulation
    2. Attention deficit
    3. Impairment in impulse control
D. Deficits in adaptive functioning skills (two or more of the following, including at least one that is criteria [1.] or [2.]).
    1. Communication deficit
    2. Social impairment
    3. Impairment in daily living
    4. Motor impairment
E. Onset of disturbance is before 18 years of age.
F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
G. The disturbance is not better explained by the direct physiological affects associated with postnatal use of a substance, other known teratogens, a genetic condition, or environmental neglect and/or abuse.

(Alternate text description for Table 1: This table shows the DSM-5 criteria for Other Specified Neurodevelopmental Disorder: Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure. The billing codes for the disorder are 315.8 (F88).)

Participants were evaluated using an interdisciplinary approach to the diagnosis, meaning that all professionals evaluated the participants simultaneously. Due to restrictions put in place as a consequence of the COVID-19 pandemic, only a certain number of team members were physically present with the participants and their families. The other team members connected to the evaluation by means of a virtual platform and utilized telemedicine to complete their assessments.

The evaluation began with a detailed interview, including questions about pre- and post-natal care, other medical, and social history. Participants were screened for hearing difficulties using a 20dB pure-tone audiometric evaluation at 1,000 Hz, 2,000 Hz, and 4,000 Hz. After the hearing evaluation, participants partook in a battery of assessments to investigate current level of functioning in areas related to diagnostic criteria for ND-PAE.

Students from the speech-language pathology graduate program conducted the static and dynamic assessment measures under the supervision of a licensed speech-language pathologist. Each participant was given an individualized testing battery which included a combination of assessments. Most of the assessments utilized by the team were norm-referenced, although criterion-referenced assessments were used occasionally. Assessments commonly used in SDRC include the *Behavior Rating Inventory of Executive Function (BRIEF-2),* which is often used to assess the participant's executive function. The *BRIEF-2* is a caregiver questionnaire in which the caregiver ranks the participant's executive function and related behaviors within the last six months. To assess for communication, a language assessment like the *Clinical Evaluation of Language Fundamentals, 5th Edition (CELF-5)* or

the *Oral and Written Language Scales, 3rd Edition (OWLS-III)* is often used. Both the *CELF-5* and the *OWLS-III* are norm-referenced assessments used to evaluate the participant's understanding and use of a variety of types of language, including receptive language, expressive language, language content, and overall language. The *Social Skills Improvement System (SSiS)* is often used to assess social skills in children and teens ages 3-18 and the *Vineland Adaptive Scales, 3rd Edition (Vineland-3)* is often used to assess adaptive function. Both the *SSiS* and the *Vineland-*3 are also rating systems ranked by the caregiver on frequency of certain behaviors. Depending on the concerns expressed by caregivers and participants, additional assessments may be used during an evaluation session. The SDRC diagnostic team also utilizes existing information, like comorbid disorders and existing diagnoses to help make the decision for diagnostic criteria.

To confirm or rule out the presence of ND-PAE, the SDRC team utilizes the combination of a detailed case-history interview, client observations during the evaluation session, norm- and criterion-referenced assessments, and the client's existing medical diagnoses. For the purposes of this study, 77 participants were evaluated using the described SDRC diagnostic procedure. Information utilized for analysis included gender, age, confirmation of alcohol and/or drug exposure, whether an ND-PAE diagnosis was given, and whether the participant was referred to a geneticist to rule out fetal alcohol syndrome or test for other syndromes. This information regarding these factors can be found in Table 2.

Table 2:

Participant Information

Total participant population	n=77
Gender	Male: n=42 Female: n=33 Nonbinary: n=0

Age:	Mean: 8.83 Median: 7.67 Standard Deviation: 6.357
Confirmed alcohol exposure:	Yes: n=73 No: n=4
Confirmed additional drug exposure:	Yes: n=72 No: n=5
Diagnosis given at evaluation:	Yes: n=53 No: n=24 (including suspected FASD but not confirmed: n=13)
Referral to genetics for further evaluation:	Yes: n=16 No: n=61

(Alternative text description Table 2: This table shows Participant Information, which includes the total participant population [n=77], gender [Yes: n=73, No: n=4], age [Mean: 8.83, Median: 7.67, Standard Deviation: 6.357], confirmed alcohol exposure [Yes: n=73, No: n=4], confirmed additional drug exposure [Yes: n=72, No: n=5], diagnosis given at evaluation [Yes: n=53, No: n=24 (including suspected FASD but not confirmed: n=13)], and a referral to genetics for further evaluation [Yes: n=16, No: n=61]).

Results

The diagnostic method used by SDRC has been utilized for 77 individuals and families over the past two years. A Spearman rho correlation coefficient was conducted to identify trends and any relationships between the study variables, including diagnosis given at an evaluation, age, gender, confirmed alcohol exposure, confirmed drug exposure. Although many of the relationships between these variables were not significantly correlated, there were relationships identified. Using an alpha of 0.05, the following relationships were identified: A negative correlation was identified between “gender” and “referrals to genetics,” r(75) = -.254, p (2-tailed)= 026. Another negative correlation was identified between “chronological age” and “confirmed alcohol exposure,” r(75) = -2.49, p(2-tailed)=0.029. Likewise, a negative correlation between the “diagnosis given at the time of evaluation” and “chronological age,” r (75) = -0.445, p (2-tailed)= <0.001. Finally, a positive correlation was

identified between "confirmation of alcohol exposure" and "confirmation of drug exposure," r (75) = 0.651, p (2-tailed)=<0.001. These results indicate that younger participants are more likely to have confirmed alcohol exposure than older participants, males are more likely to be referred to genetics, younger children are more likely to be given a diagnosis at the time of the evaluation. Finally, participants that had alcohol exposure were more likely to also have drug exposure. These results can be seen in Table 3.

Table 3

Pe*arson Product Correlation Between Variables*

			Diagnosis given at evaluation (yes=1; no=2)	Gender (male=1; female=2)	Confirmed alcohol exposure (yes=1; no=2)	Confirmed drug exposure (yes=1; no=2)	Referral to genetics (yes=1; no=2)	Chronological age
Spearman's rho	Diagnosis given at evaluation (yes=1; no=2)	Correlation Coefficient	1.000	.079	.222	.164	-.208	-.445**
		Sig (2-tailed)		.494	.053	.154	.069	.000
		N	77	77	77	77	77	77
	Gender (male=1; female=2)	Correlation Coefficient	.079	1.000	.028	-.128	-.254*	-.084
		Sig (2-tailed)	.494		.812	.267	.026	.467
		N	77	77	77	77	77	77
	Confirmed alcohol exposure (yes=1; no=2)	Correlation Coefficient	.222	.028	1.000	.651**	-.169	-.249*
		Sig (2-tailed)	.053	.812		<.001	.143	.029
		N	77	77	77	77	77	77
	Confirmed drug exposure (yes=1; no=2)	Correlation Coefficient	.164	-.128	.651**	1.000	.005	.005
		Sig (2-tailed)	.154	.267	<.001		.965	.967
		N	77	77	77	77	77	77
	Referral to genetics (yes=1; no=2)	Correlation Coefficient	-.208	-.254*	-.169	.005	1.000	.172
		Sig (2-tailed)	.069	.026	.143	.965		.134
		N	77	77	77	77	77	77
	Chrono. age	Correlation Coefficient	-.445**	-.084	-.249*	.005	.172	1.000
		Sig (2-tailed)	.000	.467	.029	.967	.134	
		N	77	77	77	77	77	77

** Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

(Alternate text description for Table 3: This table shows the Pearson product

correlation between variables. There are 6 rows and 6 corresponding columns with the following areas intersecting: Diagnosis given at evaluation (yes=1; no=2), Gender (male=1; female=2), Confirmed alcohol exposure (yes=1; no=2), Confirmed drug exposure (yes=1; no=2), Referral to genetics (yes=1; no=2), and Chronological age)

Discussion

There is ample evidence that individuals with FASD, including ND-PAE, have difficulty in areas like cognition, executive function, social skills, and more (Paolozza et al., 2014; Popova et al., 2014; Thorne, 2017). The trends identified from the SDRC data may be helpful when adding parameters to an existing diagnostic clinic, especially if referral numbers and wait lists are high. For example, the confirmation of alcohol exposure was significantly correlated with a participant receiving a diagnosis of ND-PAE. By adding questions confirming alcohol exposure to an intake form or during a case-history interview, this may increase the likelihood of an individual exposed to alcohol receiving a diagnosis of ND-PAE, and subsequently receiving services for areas of impairment.

FASD is a condition that affects an enormous population of the world, including 1 in 20 first graders in America (Lange et al., 2013; May et al., 2018; Lange et al., 2019). Unfortunately, the amount of resources available for individuals and families with FASD is lacking and the resources that are available are incredibly hard to access (Rasmussen, et al., 2010; McLaughlin et al., 2019; Cleveland et al., 2020). The diagnostic method that SDRC uses may assist other clinics in addressing the access to care for individuals and families with FASD.

There are potential limitations that clinics may encounter when attempting to implement the SDRC method. An interdisciplinary team of professionals is most appropriate

when assessing for ND-PAE, considering the variety of symptomology and criteria associated with the condition. For example, in SDRC a speech-language pathologist is able to assess for communication and social impairment, a social worker is able to assess for mood disorders, a nurse practitioner is able to assess the physicality of the patient, and a genetic counselor is able to rule out the possibility of undiagnosed genetic conditions that may explain a combination of symptoms better than an ND-PAE diagnosis. However, the professions involved in SDRC do not define the ideal professional mix for a clinic. These are the professions that are currently available for that team. In previous semesters, a psychologist and an occupational therapist have been team members and were quite useful.

Other clinics may not have access to this type of team. However, that should not discourage a clinic from attempting to identify areas of impairment. The DSM-5 diagnostic criteria for ND-PAE can be utilized as a pathway to resources (APA, 2013). If a clinic has access to only a speech-language pathologist, for example, they can confirm or rule out the presence of a) executive dysfunction, b) communication impairment, and/or c) social impairment. Subsequently, the SLP can refer for further testing by a professional qualified to identify a mood or impulsivity impairment.

FASD remains an underdiagnosed and underserved population of individuals (Paolozza et al., 2014; Popova et al., 2016; Petrenko & Alto, 2017; Thorne, 2017). By utilizing existing resources, individuals with FASD may be identified earlier and may have access to resources sooner, making the opportunity for success more achievable.

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