

Chapter 4

Fetal Alcohol Spectrum Disorders: An Unfolding Narrative



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Abstract Fetal alcohol spectrum disorders (FASDs) encompass a range of neurodevelopmental signs and symptoms that manifest as a result of exposure to alcohol in utero. FASD leads to pervasive biopsychosocial sequelae across the lifespan and intersects with significant sociopolitical issues. However, FASD remains poorly understood as evidenced in part by multiple diagnostic guidelines, lack of FDA-approved biotechnical interventions, and no validated neuropsychological diagnostic instruments. This chapter describes an interview schedule according to proposed *DSM-5* criteria for neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). It offers an empathic approach to collecting data from patients and their caretakers. The goal is to move toward a more comprehensive and consistent format for collecting data based upon current empirical understanding of ND-PAE.

Keywords FASD · ND-PAE · History · Interview · Prenatal alcohol exposure

4.1 Introduction

Fetal alcohol spectrum disorder (FASD) encompasses a wide range of physical and psychiatric signs and symptoms that arise in early childhood as a direct result of exposure to alcohol in utero. Because of protean influences of alcohol on the developing fetus, variability in amount/frequency/timing of exposure, and individual

This chapter is dedicated to Dr. Carl Compton Bell—psychiatrist, researcher, prolific writer, mentor, and warrior on behalf of the underserved. The words herein are as much his as they are mine. FASD became a part of my mission because Dr. Bell left an indelible mark on my spirit and on my practice of medicine. This chapter also is dedicated to all of the patients and mothers, grandparents, and caregivers who taught me how to speak to them about FASD. Through their painful narratives, I began to make sense of the medical and social complexity that holds this diagnosis hostage and began to search for an effective way to free patients from misdiagnosis and misinterpretation. This chapter illustrates their suffering and attempts to offer a diagnostic approach that aptly reflects their difficult life journey.

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differences in terms of nutrition and genetics, FASD carries a physiological burden that varies in terms of intensity, site, and functional impairments (Ali, Kerns, Mulligan, Olson, & Astley, 2018; Hemingway et al., 2018; Stratton, Howe, & Battaglia, 1996). According to the National Academy of Sciences, FASD is the leading cause of speech and language disorders, attention-deficit hyperactivity disorder (ADHD), specific learning disorders, and mild mental retardation (i.e., intellectual disability; Stratton et al., 1996), all of which can lead to affect dysregulation (Bell & McBride, 2010) and, in turn, to disruptive behaviors, academic failure, and psychiatric disorders in childhood. The latter often contributes to poor social and educational outcomes, including involvement in the correctional system (Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011).

A person with FASD may go undiagnosed as such or, far more often, be unsuccessfully treated for a number of comorbid diagnoses that overshadow the underlying medical disorder (Chasnoff, Wells, & King, 2015). Case in point, a patient once said to me that she had been diagnosed with “bipolar, depression, schizophrenia, borderline, and posttraumatic stress disorder (PTSD).” This complex diagnostic history is a red flag as parsimony is paramount in medicine. The same patient reported no medication (e.g., antidepressants, antipsychotics, benzodiazepines, or antiepileptics) had ever helped her feel better—again, a red flag. She did not know whether she was born at full term or with a low birth weight, but she reported a history of “heart issues” at birth and exhibited notable right-sided strabismus upon examination. She reported reaching developmental milestones without delay. However, she had difficulty concentrating in school, required special education in reading and math, and continued to struggle with poor concentration throughout her adult years. She had difficulty making friends and was bullied in school, and as an adult, she was unable to maintain gainful employment due to angry outbursts that seemingly were unprovoked. She could not make sense of why she made the same mistakes repeatedly, which led to her feeling persistently demoralized. She struggled with intermittent suicidal ideation, which had prompted my emergency room evaluation. She was unsure if her mother drank alcohol while pregnant with her but noted her mother was a recovering cocaine addict.

During mental status exam, the patient was cooperative but had poor eye contact and labile affect. She was passively suicidal, without plan or intent. She reported an auditory hallucination of a male voice whispering incomprehensibly into her ear as she fell asleep at night. She had one-third word recall and reflected poor insight when asked what she would do if she found a stamped/addressed envelope on the street. Her urine toxicology was negative; complete blood count and comprehensive metabolic panel were within normal limits. While further history revealed this patient met diagnostic criteria for PTSD and persistent depressive disorder, she did not, however, meet criteria for bipolar disorder, schizophrenia, or borderline personality disorder.

4.2 Taking History: A Jigsaw Puzzle

In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*; American Psychiatric Association (APA), 2013), FASD was offered a place in the nomenclature under the newly coined term, neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). Criteria for ND-PAE include a patient's biopsychosocial experience across the developmental trajectory, including perinatal status and interpersonal aptitude, with onset in childhood. Often, the key diagnostic criterion, confirmation of prenatal alcohol exposure, is the most challenging piece of history to collect. If a patient meets criteria for ND-PAE, evaluators may assign a diagnosis of "Other specified neurodevelopmental disorder," followed by ND-PAE, under ICD-10 code F88 (APA, 2013, p. 86).

Gathering history regarding ND-PAE is akin to assembling pieces of a jigsaw puzzle. An evaluator carries the burden of weaving together a history that (1) begins before the patient's conception, (2) will be forthcoming only when rapport has been established, (3) demands empirical soundness in order to be valid as a guide for treatment in the community or forensic decisions, and (4) supports a diagnosis that has been empirically validated (Johnson, Moyer, Klug, & Burd, 2018; Kable & Coles, 2018; Sanders, Hudson Breen, & Netelenbos, 2017; Sanders, Netelenbos, & Dei, 2020). Reaching a diagnosis of ND-PAE requires confirmed history of maternal alcohol use, which is difficult to obtain even in the best of circumstances. In order to assign a diagnosis that adequately explains a patient's presentation, informs treatment, and guides future research in the absence of confirmed fetal alcohol exposure, evaluators also must consider the gestalt, as the picture in total is more meaningful than the sum of the reported symptoms. There is a sense of déjà vu when interviewing patients with ND-PAE: the innocence of a child and naïveté of a teenager, sometimes ironically juxtaposed with interpersonal detachment and often disconcertingly suffused with the chaos of trauma and substance use. Pieces of the puzzle will appear disparate, but their gestalt tells a story that is pathognomonic of ND-PAE.

This section offers an empathic and non-shaming script for interviewing mothers of patients in the forensic setting and is organized according to *DSM-5* criteria for ND-PAE. These questions may be modified based upon whoever is providing the history (e.g., biological mother, caretaker, family member, patient). In community settings, a patient may present alone or with a caretaker, and questions may be modified accordingly. For example, an adult patient with ND-PAE might live alone or live with, and have many practical needs handled by, another adult; a child patient typically presents with a caregiver. Irrespective of age or level of functioning, patients may not always be reliable historians due to deficits intrinsic to FASD. Therefore, even in the case of independent adult patients with ND-PAE, it behooves evaluators to gather collateral data from family members whenever patients permit.

Depending upon the goal of an evaluation, there will be a variable threshold of suspicion and motivation to apply ND-PAE criteria. In the context of psychiatric

evaluations in the community setting, evaluators should apply ND-PAE criteria whenever there is concern for alcohol exposure in utero. Moreover, suspicion should be high if a mother/caretaker presents a child patient for evaluation with a chief complaint of behavioral difficulties, social deficits, academic underachievement, failure to achieve developmental milestones, or a combination thereof. Even in the case of garden variety ADHD, due diligence requires questions about birth history, which includes exposure to substances in utero. In adult patients, whether in the community or forensic setting, there should be high suspicion when the chief complaint involves functional impairments in social adaptability, financial independence, and intellectual capacity, along with mood, anxiety, and other concomitant complaints. As illustrated in the aforementioned case example, when patients report a myriad of diagnoses over time, with no improvement in symptoms despite multiple medications, and state they have never been able to make sense of their conditions, this is a red flag for prior misdiagnosis, and evaluators should consider ND-PAE as a possibility.

Another red flag is involvement in the criminal justice system as there is growing evidence that a large number of undiagnosed offenders would meet criteria for ND-PAE, if evaluated. For example, a literature review by Popova et al. (2011) found young offenders with FASD were 19 times more likely to be incarcerated than youths without FASD. Consequently, arrest or conviction alone merit consideration of ND-PAE. While incarceration and the previous examples are by no means an exhaustive list of chief complaints that should raise suspicion for ND-PAE, they are common guises that ND-PAE wears. Unfortunately, the true culprit may not be uncovered until a keen evaluator sees through the symptoms to the underlying condition.

Generally speaking, in conducting evaluations it helps to use conversational language and limit use of medical lingo (e.g., terms like gestational age, cardiovascular anomalies, midline defects, neurological deficits). It is imperative to create a non-judgmental atmosphere. Interviews should not be rushed: If an interviewee seems hesitant or unable to recall details, offer to continue at the next session. Gently address issues involving the prenatal period, especially substance use, regardless of who is providing the history. Remember, a successful intake typically requires more than one session and, above all, rapport.

Of note, patients with ND-PAE generally present for evaluation after many failed attempts to succeed in life. Evaluators should allow interviewees to tell personal narratives at their own pace. A checklist approach will not build rapport, nor will it achieve the higher purpose of healing. A key to unlocking information is empathy, as trite and obvious as this may sound. Patients and birth mothers likely are on the receiving end of this eye-opening diagnosis for the first time. Most importantly, patients, mothers, and caregivers should not be shamed; their life experiences are already replete with moments of shame and regret. Therefore, interviews should serve to mitigate, not magnify, those feelings.

After allowing an interviewee to describe the chief complaint, if there is suspicion for ND-PAE, then proceed with questions subsumed under each *DSM-5* criterion. The following interview questions are only suggestions. Evaluators should

glean the spirit of the phraseology and tailor guidelines presented here to their own styles. Moreover, to cover every point herein would require multiple sessions. Depending upon the purpose of an evaluation and time allotted to complete it, questions under each *DSM-5* criterion may be truncated. Refer to Table 4.1 at the end of this chapter for an interview template.

Table 4.1 Birth mother/caregiver interview template

Birth mother/caregiver interview template for neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)

A. Exposure to alcohol during pregnancy:

1. Timeline:

When did you find out you were pregnant?

How far along were you?

2. Social determinants of health:

What was your situation like at that time?

Did you have access to prenatal care and good nutrition?

3. Prematurity:

Was your baby born premature; i.e., before 37 weeks?

Did he/she weigh less than normal, i.e., <2500 g or < 5lbs 8 oz?

4. Midline defects:

Did your baby have a heart murmur when he/she was born?

What about a deformity in his/her upper lip or a hole in the roof of his/her mouth?

5. Fetal alcohol facies:

Would you be willing to share baby pictures?

Assess for fetal alcohol facies.

Observe patient's face for residual fetal alcohol abnormalities: Epicanthal folds, flat mid-face, indistinct philtrum, thin upper lip.

6. Maternal substance use during pregnancy:

Were you drinking socially around that time?

Were you using any other substances?

Obtain frequency, amount, and duration of use, especially for alcohol binges.

7. If unable to confirm maternal alcohol use:

Was the patient's mother drinking alcohol while pregnant with the patient's siblings?

Was anyone in the house using alcohol or other substances on a regular basis?

B. Impaired neurocognitive functioning as manifested by one or more of the following:

1. Impairment in global intellect:

Did your child have difficulty in general with academics?

Has your child ever had an IQ test? If IQ <70, patient meets this sub-criterion.

2. Impairment in executive functioning:

Poor planning and organization: *Does your child generally have a tough time planning and getting organized? Can he/she set a goal and complete it?*

Inflexibility: *Does your child easily adjust to changes in the schedule or environment?*

Behavioral inhibition: *Is your child able to delay gratification?*

3. Impairment in learning:

Academic achievement: *How far did your child go in school?*

Learning disability: *Did he/she have difficulty with subjects like math or reading?*

Special education: *Was he/she in special education classes? Which subjects?*

4. Memory impairment:

Does your child generally have a tough time with his/her memory?

Is it tough for him/her to follow instructions, especially when they involve multiple steps?

Do you find that he/she makes the same mistakes over and over again?

(continued)

Table 4.1 (continued)

Birth mother/caregiver interview template for neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)

5. Impairment in visual-spatial reasoning:

Does he/she struggle to tie his/her shoe laces or braid/comb his/her hair?

Ask the patient to tie shoelaces.

Ask the patient to draw a clock with a specific time.

***Concerning performance on any of the above tasks should alert the evaluator to recommend appropriate neurocognitive evaluations.**

C. Impaired self-regulation as manifested by one or more of the following:

1. Impairment in mood or behavioral regulation:

Labile/intense emotions:

Does he/she get into a bad mood easily, but come out of it quickly?

Low frustration tolerance and irritability:

Does your child become angry very easily, and about minor things?

Explosive temper and violent outbursts that may be verbal and/or physical:

Does he/she have outbursts where he/she raises his/her voice or becomes violent?

Does your child get into fights easily?

Legal issues:

Has he/she previously had issues with the law?

Ask about jail time, prison time, and reasons for detainment.

2. Attention deficit:

Did your child have a tough time concentrating while in school? What about now?

Can he/she complete a task once he/she starts it?

3. Poor impulse control:

Did your child have a tough time waiting his/her turn or standing in line during childhood?

Does he/she generally have a tough time following the rules in a given situation?

D. Impairment in adaptive functioning as manifested by two or more of the following, one of which must be (1) or (2).

1. Communication deficit:

Delay in acquisition of language:

Did your child start speaking later than other children?

Current speech impediments: Assess for current impediments.

Difficulty understanding spoken language:

Does your child have a tough time understanding what people are saying to him/her?

2. Impairment in social communication and interaction:

Insight:

Does your child struggle to read social cues and understand social norms?

Foresight:

Does he/she struggle to predict how his/her choices will lead to certain consequences?

Does he/she seem to have poor judgment?

Childish naivete:

Would you describe your child as childlike, naive, or concrete in his/her thinking?

Is he/she quick to trust people?

Is he/she overly friendly with strangers?

Was he/she bullied as a child?

Did he/she have a tough time making friends?

3. Impairment in daily living skills:

Delayed toileting, feeding, or bathing:

Did your child have a tough time being potty trained, learning how to bathe himself/herself, or feeding himself/herself as a child?

Difficulty managing daily schedule or personal finances:

Does he/she have difficulty managing a daily schedule (e.g., making it to appointments)?

Does he/she manage his/her own finances (e.g., pay her own bills)?

(continued)

Table 4.1 (continued)

Birth mother/caregiver interview template for neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)

4. Impairment in motor skills:

Fine motor development:

Does he/she have difficulty writing or coloring inside the lines or learning to write in cursive?

Gross motor development:

At what age did your child start crawling, walking, running?

Observe patient's gait.

When indicated, a neurological exam can help to identify ongoing deficits in gross motor function, coordination, and balance that the mother cannot identify.

E. The onset of the disturbance (symptoms in criteria B, C, D) is before age 18.

F. The disturbance causes clinically significant distress or impairment in social, academic, occupational, or other important areas of functioning.

What's your understanding of why your child has struggled with these symptoms?

Was there ever a diagnosis that helped explain these difficulties?

Was there ever a medication that helped him/her feel better?

Has there ever been a time that he/she was functioning well?

G. The disturbance is not better explained by the direct physiological effects associated with postnatal use of a substance (e.g., medication, alcohol, or other drugs), another medical condition (e.g., traumatic brain injury, delirium, dementia), another known teratogen, a genetic condition (e.g., Williams syndrome, Down's syndrome, Cornelia de Lange syndrome), or environmental neglect.

1. Traumatic brain injury:

Has your child ever been in a car accident? Did he/she hit his/her head in the accident or lose consciousness?

Has he/she ever fallen on his/her head or been hit on the head by a hard object?

2. Substance use:

Ask about cigarettes, alcohol, marijuana, cocaine, heroin.

Ask about first use, peak use, duration of use, typical use per sitting, periods of abstinence.

3. Differential diagnoses:

Complete an assessment for history of depression, anxiety, mania, psychosis, trauma, ADHD, autism spectrum disorder, and genetic disorders, in addition to substance use.

4. Suicide risk assessment:

Past and current suicidal ideation, plans

Attempts: Near attempts, aborted attempts, completed attempts

4.3 Interview Guidelines

This section includes *DSM-5* guidelines for diagnosing ND-PAE (**bold type**), with recommendations for interviewing birth mothers following each guideline.

- A. Exposure to alcohol at any time during gestation, including prior to pregnancy recognition, and the exposure level was more than minimal (i.e., more than 13 drinks in any 1 month, with no more than two drinks on any drinking occasion). Confirmation of gestational exposure to alcohol may be obtained from any of the following sources: Maternal self-report of alcohol use in pregnancy, collateral reports, or medical or other records.**

Introduction: Begin by introducing the need for gathering information. *I'd like to start with some questions about your child's birth history. This will help me get a clearer picture of how your child may have developed the problems you've described.* Keep in mind that the patient and caretaker may have approached their primary care doctor multiple times with the same complaints. There also may have been a number of conversations with school teachers or authority figures in the workplace. Very likely, there will have been multiple prior attempts to alleviate symptoms before a patient presents for mental health evaluation, whether in the community or forensic setting. By the time a patient is seeing you for evaluation, "provider fatigue" may have set in. There also may be a sense of distrust, that no one will have a solution, and that perhaps no one is truly invested in the patient's well-being. In this vein, if an interviewee questions the pertinence of birth history, then offer a legitimate reason.

Establish a timeline: *When did you find out you were pregnant? Do you remember how far along you were? If you don't mind my asking, how old were you?* The birth mother's age is a proxy for her stage of life and level of development in terms of social responsibility. A 15-year-old pregnant adolescent is unlikely to understand, or to have been educated thoroughly about, the impact of substances, nutrition, and prenatal care on the health of her developing baby. Demographics such as the mother's educational background, employment status, and number of previous pregnancies provide information that may be relevant to her behavior during the index pregnancy.

Social determinants of health: *What was your situation like at that time? Did you feel that you had the necessary support?* These questions open the door to the mother's narrative and clarify her access to resources, both economic and emotional. It creates a picture of the patient's pre/perinatal conditions while also building rapport. This information helps the evaluator adjust remaining questions if necessary and remain respectful regarding the mother's individual circumstances.

Prenatal care: *Were you able to receive prenatal care? Were you able to get prenatal vitamins? Did you take them daily? What kind of foods did you eat—that is, what was your nutrition like during your pregnancy?* Here, the evaluator is trying to assess the presence of biochemical building blocks that could mitigate effects of alcohol on the developing fetus (Thomas, Abou, & Domiguez, 2009).

Prematurity: *Do you remember if your baby was born full term? Specifically, do you recall if you were past 37 weeks pregnant when your baby was born?* If an interviewee cannot recall the exact gestational age at which the patient was born, then the evaluator should ask, *Were you close to your due date when you delivered your baby?* Then, probe for further details that could shed light on the severity and/or timing of alcohol exposure. *How much did your baby weigh when he/she was born? Even if you don't remember the exact weight because, after all, it's hard to recall these details after so many years, do you remember if your baby was less than normal weight? Did the baby need any help breathing?* Essentially, these questions reveal whether a patient was born premature

(before completing 37 of 40 weeks), had low birth weight of <2500 g or <5lbs, 8 oz. (Cutland et al., 2017), or experienced related sequelae such as immature lung development. Evaluators also could ask about “blood on the brain” or intra-ventricular hemorrhage, which sometimes is seen in premature neonates and can lead to a number of neurodevelopmental sequelae.

Midline defects: *Did your baby have a heart murmur when he/she was born? Were there any other issues with your baby’s heart? Did the doctors do a scan of your baby’s heart? Do you remember what it showed? What about any problems inside your baby’s mouth, where the upper lip or roof of the mouth had a small hole in it? Was any surgery done to repair this?* These data are a proxy for the severity of exposure to alcohol and inform both psychiatric and medical treatment. Presence of a cardiac defect at birth indicates a need for cardiology follow-up. A persistent ventricular septal defect (VSD), atrial septal defect, or more significant anomaly needs to be monitored and managed medically. Presence of a significant midline defect such as a VSD in the context of confirmed alcohol exposure in utero is a harbinger of other defects that may not be easily detected or elicited on physical exam. Again, these data alert evaluators to the possible severity of physiological damage and need for medical follow-up.

Fetal alcohol facies: Ask for baby pictures to be brought to the next visit. Fetal alcohol facies may be apparent at birth but often will recede as the patient ages. Nevertheless, a trained or seasoned evaluator may be able to observe residual fetal alcohol facies (epicanthal folds, flat midface, indistinct philtrum, thin upper lip) in adult patients, and this should be duly noted. Evaluators also should request medical records from the pre/neonatal periods and adoption records, if applicable. These records, particularly adoption records, may be difficult to obtain, depending upon the age at which a patient presents for evaluation and whether it was an open or closed adoption. Especially in forensic cases requiring the burden of proof, evaluators may seek to obtain documented evidence of this criterion. Another option may be to apply the FAS Facial Photographic Screening Tool developed by Astley (2004) and colleagues at the University of Washington.

Maternal substance use during pregnancy: *You mentioned you were two months along when you found out you were pregnant. Do you remember if you were drinking socially around that time? I know it can be hard to recall, but it would really help me get to the right diagnosis so we can help your child.* Without a doubt, this is the most challenging part of this interview. Not only does confirmation of alcohol exposure rely upon an interviewee’s remote memory, the topic also carries a psychological burden that can limit accuracy of reported history and potentially undermine the remainder of the interview. If an interviewee reports she was drinking alcohol to any extent, then the evaluator should attempt to determine frequency, amount, and duration of use. Ask about her “typical” drinking pattern in the weeks and months prior to pregnancy. If she cannot remember, ask if she typically drank on weekends, and if she agrees she did, ask if she likely drank most Friday and Saturday nights and—when she drank—did she usually get “buzzed.” It is important to use non-pejorative terms to describe intoxication. Finally—and most importantly—ask about binge

drinking (i.e., four or more alcoholic drinks per occasion) as research indicates alcohol exerts the greatest damage when given in boluses (Stratton et al., 1996).

Allow the mother to tell her narrative. Accurate history will come forth when the evaluator offers supportive body language (e.g., empathic eye contact and facial expression, body facing mother, and no note-taking if possible). Keep in mind that 40% of pregnancies worldwide are unintended (Sedgh, Singh, & Hussain, 2014). Thus, many women are unaware of their pregnancies during the critical period of organogenesis early in gestation, and even more are uninformed about alcohol's impact upon the growing fetus. In research conducted by Bell and Chimata (2015), we became aware that many mothers engaged in "social drinking" and not "alcohol abuse" in the month or two before discovering they were pregnant. Once they learned they were pregnant, these mothers abstained from alcohol, but the critical period of fetal development had already passed. It is in these moments of the interview when many mothers come to the realization that there is a connection between their actions during pregnancy and their child's lifelong suffering. Support the interviewee through the sadness such a realization likely engenders.

If an interviewee appears engaged and able to proceed, then inquire about other substances that can harm fetal brain development, such as marijuana, cocaine, heroin, methamphetamine, and nicotine. Allowing the mother to tell her story permits data to unfold gradually and, importantly, builds rapport. See below under Criterion F, Exclusionary Criteria, for a full description on characterizing use of a given substance and apply these questions to the extent that time and circumstances permit. Again, empathy is key at this critical juncture. The resulting narrative will show how the process unfolded for each mother and patient and help guide diagnosis and treatment as well as forensic conclusions.

In the event interviewees cannot recall critical information or are not forthcoming, this key criterion might remain unconfirmed. In research by Bell and Chimata (2015), maternal alcohol use was confirmed in only 87 of 224 patients (39%) who met all other criteria for ND-PAE. If an interviewee is forthcoming regarding her history of using other substances, such information may be a harbinger and veritable proxy for alcohol use but cannot serve as confirmation thereof. Therefore, if Criteria B through G are met in the absence of Criterion A, evaluators may ask for collateral information from another caretaker or reliable source: *Did you see the patient's mother drinking alcohol (using drugs) while she was pregnant with the patient or any of the patient's siblings? Was anyone in the house using alcohol or other substances on a regular basis?* Attempt to gather information about the home environment, especially if there was a partner who regularly drank alcohol. Again, these serve as proxies but do not serve as confirmation of maternal alcohol use.

B. Impaired neurocognitive functioning as manifested by one or more of the following:

1. Impairment in global intellect

An interviewee may openly describe the patient as "slow" in childhood. *Has the patient ever had an IQ test?* If reported IQ was 70 or below (actually, at or below an IQ of 75 given the 5-point margin of error), Sub-criterion #1 is met.

Otherwise, evaluators may ask patients to undergo IQ testing if evaluations require it or if treatment will be best guided by such assessment. In the case of the latter, ask the patient, *Would you be willing to take a test that helps us measure your IQ?* Then explain what IQ means and what such a test would entail.

2. **Impairment in executive functioning**

Gather information about the patient's ability to plan, organize, and delay gratification in the service of higher goals. A simple example is grocery shopping. *Does your child know how to buy groceries for the family? Does he/she make a list before going to the grocery store?* Evaluators also might ask about waiting for a coveted item to go on sale. *Does your child think about how to save money; for example, would it be typical for your child to wait for a sale before buying an expensive item he/she wanted, or would your child buy the item at full price?* Evaluators should assess for this sub-criterion as narratives unfold, noting examples of poor planning, poor organization, inflexibility, and difficulty with behavioral inhibition.

3. **Impairment in learning**

Ask about level of academic achievement. *How did your child do in school?* Allow interviewees to tell the story. If the following questions are not adequately answered in the process, then fill in the gaps. *Did he/she have difficulty with certain subjects, like math or reading? Was he/she ever told he/she had a learning disability? Did he/she receive professional help or special education services for it? Did he/she attend special education classes? How far did he/she go in school?* It may become evident the patient has lower academic achievement than expected for intellectual level. Attempt to confirm whether patients can read and write.

4. **Memory impairment**

This sub-criterion requires patient involvement, irrespective of evaluation setting. *Do you find you have a hard time remembering things?* If the answer is yes, then ask, *What kinds of things – school-related information or things that come up in daily life?* Regardless of response, administer a three-word recall test to the patient for initial memory screening (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000). *I'm going to give you three words. I'd like you to remember them for later.* An evaluator should choose three words, recite them at a rate of one word per second, have the patient repeat the three words twice, and ask the patient to repeat the words after 5 min. Hints are permitted if the patient cannot recall a word (e.g., fruit, animal, object). Duly document. Recent memory also may be assessed by asking where the patient is *right now* (i.e., name of the building, city, name of the clinic/hospital/jail/prison). Depending upon patient age, assess remote memory by asking about past presidents and/or what the patient ate for dinner. Ask caregivers: *Does your child have a tough time following instructions, especially instructions involving multiple steps? What if you asked your child to get dressed for school, pack his/her bag, and then take the trash out before catching the school bus – would your child be able to complete all of those steps, or would he/she become overwhelmed and require reminders?* Such questions high-

light difficulty with multistep instructions. These quick screening questions are only rudimentary tests of memory. Therefore, any concerning results indicate a need for more thorough assessment. *Does your child make the same mistakes over and over again, and has she ever told you she wonders why?* This is a sensitive question, and it is up to an evaluator's discretion as to when/how to present this query. In my experience, every patient I have evaluated has responded affirmatively when asked this question.

5. Impairment in visual-spatial reasoning

Visual-spatial or visuospatial reasoning involves ability to locate objects in space, which can extend to numbers, letters, and a patient's own body parts (Carroll, 1993). Deficiency may be reflected in disorganized or poorly planned drawings ("constructions") or difficulty differentiating left from right. Ask patients to draw a clock with a specific time. This may be less appropriate for the younger generation as they are more accustomed to digital clocks. If appropriate, this task can be repeated serially to assess improvement with treatment. Inquire about a patient's fine motor skills. *Can your child tie shoelaces or braid/comb his/her hair without a problem?* If circumstances are conducive, actually ask the patient to tie his/her shoelaces as you observe. Then, ask the patient to draw a picture with the patient on the right side of the picture and his/her family on the left, placing his/her signature on the bottom center of the drawing. Needless to say, the above tasks merely scratch the surface of visuospatial skills but may inform a need for further assessment.

DSM-5 notes that neurodevelopmental disorders frequently co-occur with ND-PAE (APA, 2013). Significant comorbidity occurs because fetal alcohol exposure damages the brain in myriad ways, leading to symptoms that resemble other neurodevelopmental disorders. While fetal alcohol exposure may well be the primary etiology for these symptoms, extended intake should aim to gather history that adequately explores whether patients have other neurodevelopmental disorders comorbid with ND-PAE.

C. Impaired self-regulation as manifested by one or more of the following:

1. Impairment in mood or behavioral regulation

Patients may report and/or be observed with labile emotionality (e.g., low frustration tolerance, explosive temper, irritability), including violent verbal and/or physical outbursts. These affective states generally are short-lived and do not meet criteria for a mood episode; rather, they are more accurately defined as labile mood. Try to characterize these shifts in mood and affect in order to rule out/in bipolar disorder. *Does your child become angry very easily and about minor things? Does your child have outbursts where he/she raises his/her voice or becomes violent? Has this affected his/her relationships or job situation? Does he/she get into a bad mood easily but come out of it pretty quickly? Does he/she get into fights more than most people? What's the usual reason for the fighting? Has he/she previously had issues with the law?* Ask about detention, jail, or prison time and reasons for incar-

ceration. Ask if the patient was ever committed by the juvenile court to a treatment program.

2. Attention deficit

Look for difficulties with shifting attention or sustaining mental effort. *Did your child have a tough time concentrating while in school? What about now? Can he/she complete a task once he/she starts it?*

3. Poor impulse control

In childhood, did your child have difficulty waiting his/her turn or standing in line? Does he/she have difficulty following rules in general? Did this lead to any problems, socially or otherwise? Sub-criterion 1 (emotional dysregulation) and Sub-criterion 3 (poor impulse control) may overlap, but this does not affect whether or not a patient meets Criterion C.

D. Impairment in adaptive functioning as manifested by two or more of the following, one of which must be (1) or (2)

DSM-5 describes impairment in adaptive functioning as failure to meet standards of “personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings” (APA, 2013, p. 31).

1. Communication deficit

Delayed acquisition of language: *How old was your child when he/she started speaking?* If the interviewee does not know, then ask, *Did anyone in the family or your friends ever mention your child started speaking later than expected?* Assess patients for this developmental milestone and then observe for current speech impediments. For example, there may be a notable lisp or inability to enunciate certain phonemes. Patients may have chronic difficulty understanding spoken language: *Does your child find it difficult to make sense of what people are saying?* With age, patients may find ways to compensate for the latter, but interviewees likely will offer examples of this point if they are relevant and memorable.

2. Impairment in social communication and interaction

Look for insight and foresight. *Is your child quick to trust people? Is he/she overly friendly with strangers? Has this led to any problems?* Patients may report and/or be observed to be childlike, naïve, or concrete in thinking. They may have had difficulty reading social cues and understanding social consequences and as such will report or exhibit poor judgment and limited ability to foresee the consequences of their choices. *Was your child bullied as a child? Did your child have a tough time making or keeping friends?* Patients may pointedly state they really want people to like them and do not know why they have been ostracized for much of their lives.

3. Impairment in daily living skills

Look for delayed toileting, feeding, or bathing in early childhood and difficulties managing daily schedule or personal finances later in life. *Did your*

child have any issues with being potty trained, learning how to bathe, or feeding himself/herself as a child? During your child's teen and adult years, did he/she have difficulty managing a daily schedule? Does he/she manage his/her own finances?

4. Impairment in motor skills

Fine motor development: *Did your child have difficulty writing or coloring inside the lines?* Delayed attainment of gross motor milestones: *How old was your child when he/she started crawling, walking, running?* If interviewees cannot recall, then ask, *Did anyone in the family ever say your child crawled/walked a little later than expected? Does your child have any difficulty throwing or catching a ball? Did your child have difficulty learning to write cursive? Does your child have "butter fingers" or spill things often?* Observe the patient's gait. If circumstances permit, have patients throw and catch a ball. When indicated, a neurological exam may help to identify ongoing deficits in gross motor function, coordination, and balance that patients are unable to articulate.

E. Onset of the disturbance (symptoms in Criteria B, C, D) is before the age of 18 years

F. The disturbance causes clinically significant distress or impairment in social, academic, occupational, or other important areas of functioning

Criteria E and F should be clear by the time Criteria A–D have been addressed. Still, if an interviewee has not clarified level of functional impairment and distress by this point, the evaluator should elicit the patient's personal sense about his/her symptoms, such as: *What's your understanding of why you've struggled with these symptoms? Was there ever a diagnosis that helped explain your difficulties? Was there ever a medication that helped you feel better or helped you function the way you wanted to in your life?*

G. The disturbance is not better explained by the direct physiological effects associated with postnatal use of a substance (e.g., medication, alcohol, or other drugs), another medical condition (e.g., traumatic brain injury, delirium, dementia), another known teratogen (e.g., Fetal Hydantoin Syndrome), a genetic condition (e.g., Williams Syndrome, Down's syndrome, Cornelia de Lange syndrome), or environmental neglect

This exclusionary criterion demands that evaluators have (a) acquired sufficient evidence that exposure to alcohol in utero was the proximal cause of presenting symptoms, and (b) ruled out all other possible explanations for patient symptoms in the service of parsimony. This diagnostic criterion also serves to remind evaluators that there may be multiple comorbid factors contributing to the patient's presentation. For example, individuals with ND-PAE may place themselves unwittingly in high-risk situations due to poor insight. Therefore, it is important to ask about traumatic brain injury (TBI), as such injury may exacerbate existing symptoms and/or lead to new symptoms affecting cognition and adaptive functioning. *Has your child ever been in a car accident? Did he/she hit his/her head? Did he/she lose consciousness? For how long? Did a doctor*

examine him/her? Has your child ever fallen on his/her head or been hit on the head with a hard object? Did he/she lose consciousness? Did he/she go to the emergency room? Did he/she ever get a brain scan or picture of his/her brain? Did a doctor ever say there was blood on his/her brain or that his/her brain was injured? History of TBI does not preclude an ND-PAE diagnosis; rather, a history of risk-taking behavior in ND-PAE may inadvertently lead to TBI.

Approximately 50% of individuals with mental illness will have a comorbid substance use disorder in their lifetime (National Institute on Drug Abuse (NIDA), 2020). Individuals with ND-PAE are at even greater risk of substance abuse. Consequently, obtaining substance use history is imperative in treatment planning and forensic contexts, as it sheds light on factors that may have contributed to behavior. *I need to ask you a few questions about substance use, because using substances like alcohol can make your child's current symptoms worse in the long run. Do you know if your child smokes cigarettes? Has he/she ever tried alcohol, marijuana, cocaine, methamphetamine, or heroin?* After asking about a given substance, pause for interviewees to reply, then ask about the next substance. Finally, ask if there are any other substances: *Has your child ever tried anything else, maybe Ecstasy or PCP or huffing inhalants?* Next, characterize use of each substance across the patient's lifespan. *Let's talk more about XX. How old was your child when he/she first tried it? Since then, how often has he/she used it? How much did he/she use each time?* Alcohol may be quantified according to milliliters or ounces of hard liquor/wine/beer, while other substances will be measured according to grams, bags, or cost. Gather history regarding typical parameters: first use, peak use, duration of use, and periods of abstinence around each substance. Asking about attempts to abstain and past treatments can open up a conversation about healing. Once again, the presence of a substance use disorder does not preclude a primary diagnosis of ND-PAE, but differential diagnosis is essential for appropriate treatment planning that includes limiting further injury to already damaged organ systems and neuronal circuitry.

As is necessary in any valid psychiatric or psychological intake, basic diagnostic categories must be covered: depression, anxiety, mania, psychosis, and substances. PTSD also should be included, especially in the case of putative ND-PAE. In addition, evaluators should touch upon basic neurodevelopmental diagnoses such as ADHD, learning disability, and autism spectrum disorder. Even when fetal alcohol exposure is confirmed, patients may meet bona fide criteria for another *DSM-5* diagnosis and may benefit from related interventions. In sum, a complete psychiatric or psychological evaluation involves questions about major/persistent depressive disorder, bipolar disorder, generalized anxiety/panic disorder, posttraumatic stress disorder, substance use disorders, schizophrenia, psychotic symptoms in the context of all of the aforementioned, as well as other neurodevelopmental disorders such as ADHD.

History offers numerous examples of misdiagnosis. For example, individuals with autism spectrum disorder have been misdiagnosed with schizophrenia (Gama Marques & Pires, 2019), and African-Americans with bipolar disorder have been misdiagnosed with undifferentiated schizophrenia and prescribed

antipsychotics instead of lithium, the gold standard treatment (Bell & Mehta, 1980). Adult patients with ND-PAE often present with a prior diagnosis of bipolar disorder based upon persistent emotional dysregulation, which, as delineated above, needs to be accurately characterized for valid differential diagnosis. Anecdotally, individuals with ND-PAE also may report late-onset auditory hallucinations that began in their 30s (as described in the case example). On further characterization, hallucination content often does not comport with symptoms in schizophrenia where patients may hear either a running commentary, one or more voices arguing, or one's own thoughts out loud. Adult patients with ND-PAE also have more interpersonal skills than schizophrenics, albeit impaired, and do not manifest the negative symptoms seen in schizophrenia. Child patients with ND-PAE may present with some combination of reactive attachment disorder, disruptive mood dysregulation disorder, intermittent explosive disorder, and/or ADHD in addition to other neurodevelopmental disorders. Adolescents with ND-PAE often present with oppositional defiant disorder or conduct disorder. While a patient may meet criteria for one or more of these diagnoses, an etiological explanation of fetal alcohol exposure can support the more parsimonious diagnosis of ND-PAE.

Lastly, evaluators should conduct a suicide risk assessment. This involves inquiry into past and current suicidal ideation, plans, near attempts, aborted attempts, and completed attempts. According to research by Thanh and Jonsson (2016), life expectancy for persons with fetal alcohol syndrome is 34 years on average, with "external causes" accounting for 44% of deaths. Suicide was responsible for 15% of deaths, followed by accidents at 14%, and poisoning by recreational substances at 7%. In one of Bell's commentaries, he wanted to call attention to "a biologic etiology of suicidal behavior" in FASD (Bell, 2017), which posits that affect dysregulation leads patients to engage in risky behaviors such as substance use, violence, unsafe sexual practices, and suicide. Therefore, suicide risk assessment is extremely important in the context of ND-PAE. It behooves an evaluator to obtain a complete narrative of suicidal history rather than simply going through a checklist, not only to determine patient risk profile in the context of affect dysregulation and impulsivity but also to understand how the patient typically copes with stress (i.e., adaptive behavior).

4.4 Concluding Remarks

Recent research finds that FASD is far more prevalent (May et al., 2018) and at the root of more extensive psychopathology (Popova et al., 2016) than previously realized. As such, *DSM-5* has proposed a set of criteria under the diagnosis ND-PAE to facilitate mental health assessment of the central nervous system dysfunction in FASD. Accurate diagnosis requires a comprehensive assessment that includes neonatal and neurodevelopmental status, childhood educational trajectory, mood/affect regulation, and adaptive functioning across the lifespan. The assembled pieces of

this jigsaw puzzle reveal a picture in bas relief that goes beyond individual criteria to portray an individual who struggles to comprehend and self-regulate yet persistently experiences a sense of underachievement without the means to reroute. Like intellectual disability and autism, ND-PAE impacts patients across all areas of functioning throughout life. A supportive interview process can move a patient one step forward toward a better understanding of symptoms. Similarly, using *DSM-5* criteria in a systematic manner can move the field one step forward within a validated framework for understanding ND-PAE. Such understanding should remain couched in each patient's rich narrative, and our medical understanding of ND-PAE should be refracted through a sociopolitical lens that informs larger shifts that are needed to prevent this multifaceted and debilitating disorder in future generations.

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