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At a Glance…..A brief overview of Fetal Alcohol Syndrome for practitioners (FAS)

Abstract

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) are caused by prenatal alcohol exposure (PAE). It causes epigenetic changes, permanent neurodevelopmental deficits, and anomalies in growth and facial structure. This 'At A Glance' article highlights that health and social care practitioners should be aware of the impact of FASD on the individual, the family, and the community to provide the best preventative and supportive care possible.

Introduction

Alcohol is used despite concerns that it can cause physical, social, mental, and economic issues (NHS Digital, 2019). Alcoholic beverages contain different percentages of ethanol, all of which are teratogenic. One form of long-lasting damage that can be caused by alcohol is Fetal Alcohol Syndrome (FAS), also known as part of the umbrella term Fetal Alcohol Spectrum Disorders (FASDs). Fetal Alcohol Syndrome affects individuals and families in a variety of ways including neurological (Lamb, et al, 2019) social (Lees at al, 2021) and physical complications (May et al, 2015), it is important to raise awareness, consider preventative strategies, and the possibility of mitigating further damage (Stade et al, 2009). Prevalence of FASD is difficult to determine (Schölin et al., 2021b).

What is Fetal Alcohol Spectrum Disorder and Fetal Alcohol Syndrome?

Alcohol is a teratogen, it has a toxic effect on the developing fetus (British Medical Association, 2007b). Fetal Alcohol Spectrum Disorder (FASD) is seen as a non-diagnostic umbrella term (Blagg and Tulich, 2018, Nash and Davies, 2017, Riley et al., 2011), encompassing a wide range of disabilities as a result of Prenatal Alcohol Exposure (PAE)(Guerri et al., 2009), such as: Partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Neuro-developmental disorder (ARND), Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE), Alcohol-Related Birth Defects (ARBD) and Fetal Alcohol Syndrome (FAS). FAS is the only diagnosis officially recognised and standardised within the ICD-11(WHO, 2021). The other terms often describe a subset of the FAS's criteria (British Medical Association, 2007a).

FASD can be diagnosed at different stages in a person's life, as the PAE causes lifelong irreversible developmental changes. As a fetus, the teratogenic effects of alcohol may be observed antenatally, but this is a rare occurrence (Welch-Carre, 2005). More often FASD is diagnosed during their early childhood or later in life. There is also evidence that PAE has an epigenetic effect, meaning that it alters the DNA of the child and continues to do so throughout their lifespan. Data has furthermore shown that alcohol can impact the epigenome (the part of the genes that you pass on), meaning that it can impact future generations (Lussier et al., 2017).

Prevalence

Fetal alcohol spectrum disorders remain under-diagnosed, many children are either misdiagnosed or undiagnosed (Chasnoff, Wells and King, 2015). British Medical Association (2007b) suggest that the reason for this is complex and suggest the following: (Table 1)

Table 1

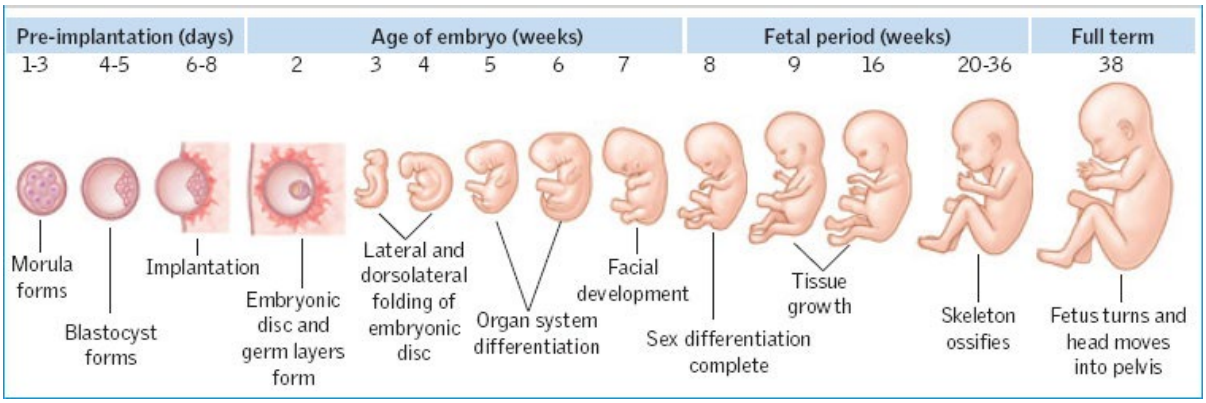
Reasons for undiagnosed FASD (BMA, 2007a)
Lack of a specific diagnostic test .
Under-reporting of maternal alcohol consumption, or lack of maternal alcohol history.
Difficulty in detecting the defining features associated with FASD in neonates.
Confounding factors (e.g., poor nutritional maternal status, polydrug use).
Differing and poorly defined diagnostic criteria for FASD.
The lack of multidisciplinary neurodevelopmental teams to complete comprehensive assessments needed to evaluate the full range of FASD.
A lack of knowledge and understanding of FASD among healthcare professionals, making them feel not competent to make a diagnosis.
Several genetic and malformation syndromes that display similar clinical features as FASD (e.g., Williams syndrome and DiGeorge syndrome)

In the UK, there have been several estimates of children with FASD ranging from 3.2% (Wise, 2019) to 6.0% - 17% (May et al, 2015, McQuire et al., 2019). It has also been stated that there are no reliable estimates of prevalence of FASD in the UK (Schölin et al., 2021b). Alcohol use in women during pregnancy within the UK may provide some indication of the incidence of FASD, however these figures are also not seen as fully representative, as they are commonly reliant on self-reporting (Mukherjee et al., 2013). Studies in the past 20 years show antenatal alcohol use differs widely; the latest data provided by Office for National Statistics (2018) identified that in 2017 11.3% of interviewed pregnant women admitted to having drank alcohol in the previous week. Nykjaer et al. (2014) conducted research that displayed a far larger percentage of alcohol use during pregnancy in the UK, with 79% during the first trimester, 63% in the second and 49% in the third. Based on these figures the amount of FASD may be far higher than previously stated.

Aetiology

Maternal alcohol consumption is the cause of FASD and FAS, however the evidence is inconclusive as to why some children are impacted more than others. Genetics, nutritional status of the mother, polydrug use have been offered as variables (BMA, 2007b). Gestation is divided into three trimesters, each trimester has different purposes for fetal development and growth (Figure 1). Alcohol consumption in the first trimester can result in irreversible cranio-facial alterations (Popova, et al, 2017). Figure 1 illustrates the development at this point and highlights that in the first trimester, facial development is taking place. Alcohol exposure in the second and third trimesters can result in ongoing damage to the brain (Popova et al, 2017). Recent government advice reflects the evidence base (Schölin, 2021b), the current advice from the Chief Medical Officer is no alcohol during pregnancy (Department of Health, 2016). However, an unplanned or undetected pregnancy could result in the woman not being aware that she is pregnant and therefore unknowingly expose the fetus to alcohol (Schölin et al., 2021b).

Figure 1: Fetal and embryo development (Hendry at al, 2012)



Clinical features

Several clinical features can develop because of prenatal alcohol exposure, these can be physical (table 2) as well as cognitive and social. Not all these features may present themselves in all instances of FASD or FAS and they can differ based on the extent of the exposure. Practitioners should be aware that there are different physical presentations within ethnic groups (Del Campo and Jones, 2017).

Physical features (adapted from Del Campo and Jones, 2017) (Table 2)

Growth	Growth faltering: Both height and weight when compared to those from the same ethnic origin and can be observed pre- and post-natal.
Structural defects CNS/Brain	Microcephaly, small head circumference of 10% less than average. Central Nervous System damage or defects which include agenesis (absence) or partial-agenesis (partial absence) or dysgenesis (defective development) of the corpus callosum (the connective white matter between the brain halves) and the cerebellum (part of the brain that deals with motor skills). Furthermore, an overall reduction of the brain volume in all areas has been reported.
Eyes	Ptosis: Hanging or 'drooping' eyelids. Short palpebral fissures: The opening of the eyelids is not as wide as in people born without FASD. This is also a marking of the severity of FASD, as it is associated with a lower IQ. Strabismus: Eyes are not properly aligned. This is not specific to FASD, as it can be a feature in many other conditions.
Epicanthal fold	Extra skin that may covers the inner canthi of the eyes. These folds can be considered natural in certain ethnic groups, as it is a common feature in Asian and Finnish people.
Mouth	Philtrum: Smooth and long Upper lip: Thinner than 'normal'. See Figure 2.
Nose	Short, anteverted (upturned nose). Low/flat nasal bridge
Midface	Hypoplasia, the upper jaw, cheekbones and eye sockets have not fully developed.
Ears	'Railroad ears' The top curve of the outer ear is underdeveloped and folded over, parallel to the curve beneath it, giving the appearance of a railroad track, see figure 3. (Wattendorf and Muenke, 2005)
Joints	Contractures of one or more joints.

Hands	Hands can display abnormal palmar creases, shaped like hockey sticks with a sharp curve towards the second and third fingers. Camptodactyly: the permanent bending of one or more fingers, See figure 3.

Figure 2: Lip/Philtrum Guides (Hoyme et al., 2016);

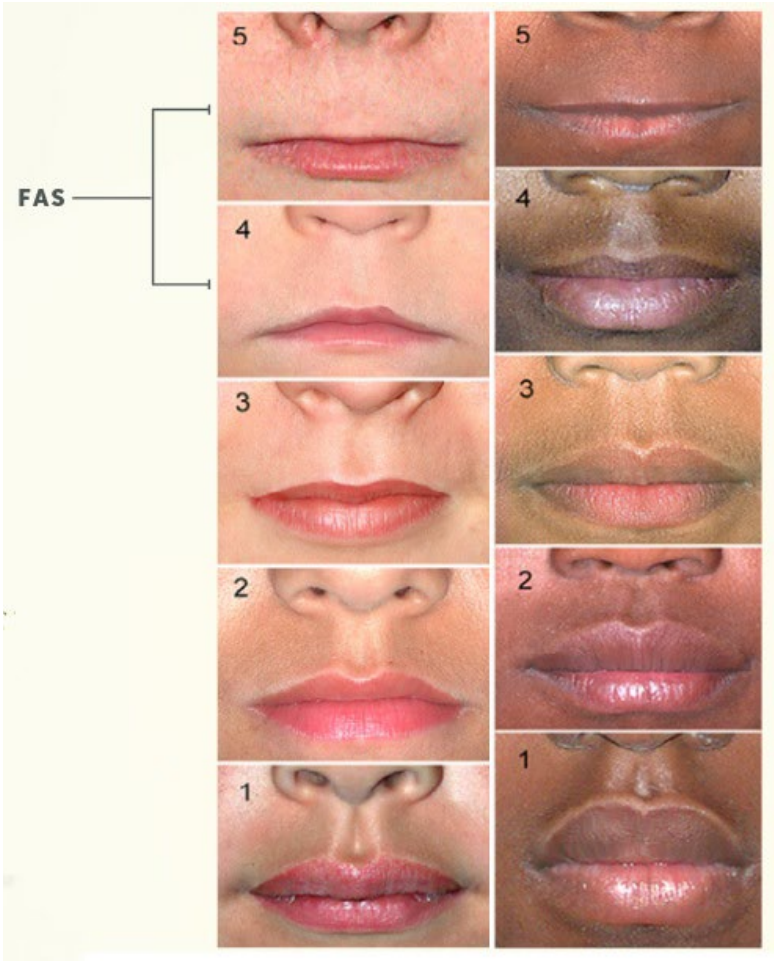
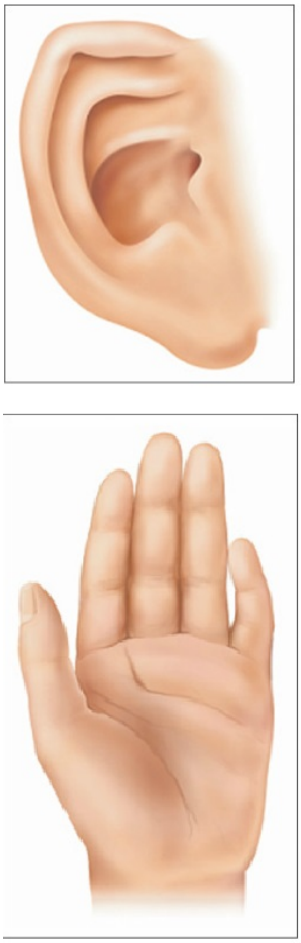


Figure 3: Railroad Ear and hand with Hockey stick crease and camptodactyly (Wattendorf Muenke, 2005)



There are over 400 co-occuring conditions related to FASD, which as displayed above, is not solely about 'the face' (National Organisation for FASD, 2021) Only 10% of children with FASD have physical features (National Organisation FASD, 2021), many more have conditions related to their executive functioning this impacts on the affected person in multiple ways including (Lamb, et al, 2021),

- Learning and remembering
- Understanding and following directions
- Controlling emotions
- Communicating and socializing
- Daily life skills, such as feeding and bathing

- Impulsivity, hyperactivity,
- Increase susceptibility to victimization and involvement in the criminal justice system (fast and conry, 2009)

Impact on individuals

Diagnosis can impact on an individual considerably, their reaction may vary. Families experience a sense of grief, loss and guilt following diagnosis (Leenars et al, 2012). The health and social care practitioner's role is to support the whole family through any adjustment and ensure their needs are met. An early diagnosis, and adequate information and support for the family can reduce the risk of subsequent children being born with FASD/FAS (Murkerjee, 2007). Many children with FASD may become Looked After Children as a result of safeguarding concerns including PAE, often FASD will be diagnosed at a later date when behavioural or learning needs become pronounced. (BMA, 2007a, Carellas, 2021). It is important to note, excessive alcohol consumption can be an indicator of an inability to provide a protective environment for a child. US data suggest that the rates of FASDs are higher than those of Autistic Spectrum Disorder, and yet there is more support available for children with ASD (Carellas, 2021).

Practitioners/professionals role

Sexual health practitioners, GPs, practice nurses should consider contraceptive advice and family planning to reduce the risk of alcohol exposed pregnancy. Access to training on how to provide preventative interventions through motivational interviewing has been proven to reduce this risk (Schölin et al, 2021a). Schools and Early Years Professionals also need to be aware of the condition to ensure that children are assessed and receive the appropriate support (Lees et al, 2021). When asked about alcohol consumption people are not always able to provide an accurate answer, either they may not recall accurately or underestimate. Building a trusting relationship with families particularly women can increase the potential for authentic self-reporting (Schölin et al, 2021a).

Clinical consideration and key points

- This article reiterated the importance of Making Every Contact Count, alcohol consumption is a public health concern (Health Education England, 2021).
- Alcohol consumption can also lead to ill health for women, which increases morbidity and mortality (BMA, 2007b).
- Very few parents intentionally want to harm their child, therefore when FASD is diagnosed, we need to ensure we are sensitive to the whole family (Leenaars et al, 2012).
- Safeguarding concerns surrounding alcohol consumption must be escalated to a designated safeguarding officer.

Reflective Questions

- Do health and social care professionals understand the negative impacts of alcohol consumption?
- Are health and social care professionals good role models with regards to alcohol use?
- If a woman drinks alcohol whilst they are pregnant, should this be a safeguarding issue?

- Do you think a child should be able to sue their parent for the effects of consuming alcohol or drugs whilst they were in utero, please refer to Larcher and Brierley (2014)?
- How can health and social professionals share this message with their patients, clients and public?

Key words	Meaning
Teratogen	An agent or factor which causes malformation of an embryo.
Epigenetic	Change in genetics without changing the DNA sequence
Fetal	From 8-10 weeks of gestation
Embryo	Conception to 8 weeks
Ethanol	Chemical compound and the active ingredient in alcohol

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