FOETAL ALCOHOL SPECTRUM DISORDERS: A HIDDEN DISABILITY

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ABSTRACT

Foetal alcohol spectrum disorder (FASD) is a lifelong, persistent condition caused by prenatal exposure to alcohol. Research suggests a deficit in health-care professional's knowledge surrounding the symptomatology and treatment of FASD, which can result in misdiagnosis or missed-diagnosis of the condition. Psychologists can play a key role in the identification and treatment of FASD. Thus, in order to create awareness of FASD among psychologists, this article will provide general information on FASD, including existing diagnostic challenges, an overview of primary and secondary disabilities associated with the condition, and will conclude by summarising recommended strategies for supporting clients impacted by FASD.

INTRODUCTION

Alcohol is a potent physical and behavioural teratogenic agent that plays a complex role in Irish society[1,2]. There are a myriad of health implications associated with the consumption of alcohol, including devastating long-term effects on the normal developmental progression of the foetus[2]. Consequently, national guidelines for the USA, UK, New Zealand and Australia recommend complete abstinence from alcohol during the gestational period, and the HSE in Ireland is advising pregnant women that there is no amount of alcohol that is considered safe during pregnancy[3].

Alcohol has been identified as a direct cause of Foetal Alcohol Spectrum Disorders (FASD)[4], which is a term used to describe a continuum of life-long persistent conditions caused by prenatal exposure to alcohol and is internationally recognised as the leading preventable cause of birth defects[5]. In 2012, the National Substance Misuse Strategy Steering Group launched a report addressing the future direction of policies to deal with the use and misuse of alcohol in Ireland. The report contained a number of recommendations, including promoting greater awareness of FASD among

healthcare professionals in order to improve the diagnosis and management of alcohol related disorders[1]. While there has been a gradual progress in this regard, international research has revealed that there remains a significant lack of awareness and knowledge regarding FASD among health professionals[6, 7], including psychologists[8]. Psychologists can play a crucial role in recognising, diagnosing and treating individuals with FASD to ensure that those affected receive prompt and comprehensive treatment[8]. Thus, this article aims to create awareness of FASD among psychologists in Ireland by providing general information on common symptoms, diagnostic challenges and treatment strategies associated with the condition.

FOETAL ALCOHOL SPECTRUM DISORDERS

Foetal alcohol spectrum disorders (FASD) is an umbrella term that encompasses the range of consequences following prenatal exposure to alcohol[2]. The two main conditions subsumed under the spectrum include Foetal Alcohol Syndrome (FAS) and Alcohol Related Birth Defects (ARBD)[9]. FAS is the most severe and identifiable form of FASD and is associated with a range of mental and physical defects including dysmorphic facial features, brain damage, congenital anomalies, stunted foetal growth, along with cognitive, behavioural, emotional and adaptive functioning impairments[2,4,10]. International diagnostic guidelines define the cardinal facial features associated with FAS, including short palpebral fissures (small eye openings), smooth philtrum (vertical groove between nose and upper lip) and a thin upper vermillion border[2] (upper lip). However, while FAS requires the presence of facial dysmorphology[11], there are also a wide range of cognitive (e.g. intelligence, attention), social (e.g. communication) and adaptive (e.g. problem solving and decision making)[5] deficits related to prenatal alcohol exposure[9]. Thus, the term Alcohol Related Birth Defects (ARBD) was later coined to describe the cognitive and behavioural deficits that manifest as a result of prenatal alcohol exposure in the absence of any physical characteristics[9,11]. In recent years, 'FASD' has been introduced as a non-diagnostic descriptive term to refer to the diagnosable conditions associated with prenatal alcohol exposure, including FAS and ARBD[12]. However, in the absence of physical features, FASD can often be overlooked or misdiagnosed [13, 14] and consequently has been professed as a 'hidden disability'[15].

PREVALENCE/DIAGNOSIS

There is currently no national register to capture the number of people with FASD in Ireland[1], thus the exact prevalence is unknown[16]. However studies on self-reported alcohol consumption throughout pregnancy have revealed that alcohol use is prevalent and socially pervasive among pregnant women in Ireland[10,17]. For example, a study of women who attended

the Coombe Hospital in Dublin between 1987 and 2006 found that 79% of Irish women reported alcohol consumption during pregnancy[18], while the Screening for Pregnancy Endpoints research (SCOPE)[17] study reported a similar figure of 80%. Interestingly, The Growing Up in Ireland (GUI)[19] study reported a significantly lower rate of alcohol consumption during pregnancy, ranging between 20-40%. Unfortunately, recent research published in the Lancet [4] reflected the accuracy of the higher figures, as Ireland ranked among the top five European countries with the highest level of alcohol consumption during pregnancy, as well as consequent cases of FAS. However, it is estimated that FAS comprises only 10-15% of all FASD cases and has the most explicit diagnostic criteria[13], while up to 75% of people with FASD present with no characteristic dysmorphic features and may go undiagnosed[20].

It has been postulated that the worldwide prevalence of FASD may escalate in the coming years due to an increase in binge drinking, consumption of alcohol during pregnancy and a growing rate of unplanned pregnancies[17,21]. Despite this projection, there is currently no standardised assessment, diagnostic service or treatment pathway available for individuals with FASD in Ireland[14, 20]. Therefore health professionals in an Irish context are encouraged to utilise a range of international diagnostic systems to guide their assessment. A plethora of diagnostic guidelines for FASD have been developed such as the 4-digit diagnostic code[22], the Canadian Guidelines[23] and the revised guidelines of the Institute of Medicine[24]. Most of these classification systems are multifaceted[25] as a multi-disciplinary approach is considered best practice to accurately assess and interpret the wide range of outcomes that define FASD[22, 24, 26]. However, because no universal list of symptoms has been established for FASD, these varying diagnostic systems may lead to contradictory outcomes[26.] To address this lack of diagnostic clarity, diagnostic criteria for cognitive and behavioural effects associated with prenatal alcohol exposure have recently been introduced to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5). Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) is included under the appendix section entitled 'conditions for further study'[11]. The DSM-5 criterion for ND-PAE requires confirmation of prenatal alcohol exposure and impairment in three domains, including neurocognitive functioning, self-regulation and adaptive functioning [11, 25, 26]. Although there is considerable overlap in the criteria for FASD diagnostic instruments and ND-PAE, a review by Sanders and colleagues (2017) found that ND-PAE was less sensitive in identifying clients with FASD. Therefore, it is suggested that health professionals adopt a multi-disciplinary approach to accurately assess and interpret the wide range of outcomes that define FASD[22, 24, 26].

As part of a multidisciplinary assessment, it is recommended that health professionals incorporate questions about prenatal alcohol and substance use into their assessment procedure[26]. Social desirability bias and stigma can affect self-report measures of alcohol consumption during pregnancy[27]. Therefore, stringent clinical protocols in healthcare settings are required to ensure accurate screening. A proposal calling for alcohol testing throughout routine pregnancy check-ups was recently passed at the annual conference for the Irish Medical Organization (IMO)[28]. This measure aims to reduce the incidence of FASD in Ireland and provides medical professionals with the opportunity to intervene in cases where alcohol is being consumed during pregnancy[29]. However, while educating women on the risks of prenatal alcohol exposure is important, FASD prevention strategies should aim to address and eliminate factors contributing to alcohol use during pregnancy, rather than reinforce notions of individual and personal responsibility and blame[30].

PRIMARY AND SECONDARY DISABILITIES

Individuals with FASD may present with both primary and secondary disabilities. Primary disabilities refer to the impaired mental functioning that directly results from prenatal alcohol exposure, such as deficits in cognition, social skills and adaptive behaviour as well as attention/ hyperactivity[26]. For example, impairments associated with executive and adaptive functioning are hallmark deficits of FASD[31]. Executive function deficits can contribute to impulsivity, impaired planning, emotional regulation and memory, as well as a diminished ability to learn from consequences[26]. In addition, deficits in adaptive functioning can impair an individual's communication, socialisation and mental capacities to deal with everyday challenges[31].

Although FASD is a common cause of intellectual disability [5] it has been reported that up to 86% of individuals with FASD have an IQ within the normal range. However, their academic ability, communication, living and adaptive behaviour skills are often below their IQ levels. For example, a person with an IQ of 80 may have a math IQ of 70, socialisation skills of 65, and adaptive behaviour skill of 60[32]. Despite this, there tends to be a reliance on standardized intelligence tests in the assessment of clients with suspected FASD, which fail to detect cognitive deficits associated with the condition[33]. Thus, in instances where intellectual capacities are not diminished, cognitive deficiencies are usually present which can limit an individual's ability to perform everyday tasks. It is therefore suggested that adaptive behaviour composite scores may be better predictors of outcomes than IQ[12].

In addition to primary disabilities, individuals with FASD are at risk of developing secondary disabilities[33], which

are not present at birth but occur as a result of FASD and could presumably be ameliorated through greater understanding and appropriate interventions[32]. Examples of secondary disabilities include mental illness (e.g. mood disorders), behavioural disorders (e.g. ADHD, Conduct Disorder, Oppositional Defiant Disorder), substance use disorders, academic difficulties and employment issues[26]. Rates of secondary disabilities are significantly high in individuals with FASD, particularly throughout adolescence and adulthood[34]. In fact, it has been estimated that up to 94% of people with FASD have experienced at least one mental health problem throughout their life, 60% have encountered trouble with the law, 50% have been confined in jail or a psychiatric treatment facility, 49% have engaged in inappropriate sexual behaviours and 35% have had issues with drug or alcohol abuse[33, 34].

KEY ISSUES FOR CLINICIANS

Many of the symptoms associated with FASD are similar to mental health disorders[26]. However, as FASD is not considered a psychiatric condition, it is often overlooked by mental health professionals and can therefore be misdiagnosed as a co-occurring mental health condition. Co-occurring disorders with FASD can create obstacles to appropriate treatment, as it is postulated that various mental health disorders that are more readily diagnosed will be observed in clients with FASD and thus become the primary diagnosis in determining treatment. For example, attention deficits and hyperkinetic activity associated with FASD may be misdiagnosed as Attention Deficit Hyperactivity Disorder (ADHD) by medical professionals, and therefore treated with inappropriate treatment methods. The most common misdiagnosis and co-occurring mental health conditions in children and adolescents with FASD include ADHD, autism spectrum disorders, substance abuse disorders and conduct disorder[12]. Although these diagnoses may fit the client's behaviour, they often don't fully accommodate their difficulties, and clients are more likely to develop secondary conditions when their individual needs are not recognised or adequately supported[33]. Furthermore, failure to identify FASD can be detrimental to the client's treatment, as clients with FASD and a co-morbid disorder are more likely to have adaptive behaviour problems compared to those diagnosed with a mental health disorder and no FASD[12]. It is also important to note that research identifying associations between mental health symptoms and FASD purportedly contains a number of methodological limitations such as referral bias and influence of uncontrolled cofounders[35].Therefore, while there is concern for FASD being misdiagnosed as another disorder, there is also risk for a false positive FASD diagnosis when this relationship is overestimated[36]. Given the complexity in the classification of FASD, it

is crucial that psychologists are familiar with the common symptomatology of FASD in conjunction with typical comorbid disorders, in order to ensure clients benefit from a suitable treatment approach.

TREATMENT APPROACH

Although some professionals are concerned about the stigma attached to a FASD diagnosis[37], a true diagnosis has been identified as a protective factor as it allows for early intervention and suitable supports[8]. Treatment of clients with FASD can be challenging. Given the variability in physical and behavioural outcomes[2], individuals with FASD present with a unique profile and often respond differently to treatments when compared to those with other neuro-developmental disorders[20]. However, there are a number of steps psychologists can take in order to communicate with clients with a suspected FASD and maximize the effectiveness of treatment[33].

Communication of an FASD diagnosis should be carried out in a manner that minimizes any potential harm to the client and their relationship with their mother. Thus, the clinician should ensure that the client understands how FASD can be caused inadvertently, including the mother's lack of knowledge around negative effects of alcohol, difficult life circumstances or mental health issues. It is imperative that information is shared with the client in a developmentally appropriate manner, using age-appropriate language, as communication can be challenging with this population[38]. For example, there is often a marked discrepancy between an individual's ostensibly high verbal skills and their ability to communicate effectively[39]. Psychologists should therefore ensure that they use simple, concrete language and avoid complex questions that may result in individuals with FASD responding with factually incorrect responses or becoming emotionally unavailable[26, 31]. Role plays using different reactions and outcomes have also been identified as an effective tool in helping clients with FASD communicate and learn about cause and effect[26, 39].

In addition to communication impairments, learning and memory deficits associated with FASD necessitate the use of consistency and repeating information in order to establish a sense of control and predictability. Furthermore, clients with FASD have a tendency to be talkative and charming, which can lead psychologists to overestimate their competence and comprehension of intervention goals. Thus, it is advised that information is repeated and the individual with FASD demonstrates their knowledge of the intervention or question asked by explaining it in their own words[31].

The environmental context is also very important to consider when treating individuals with FASD. For example, it is postulated that this population are conducive to learning in a stable environment with minimal change in order to minimize anxiety that can impede the

therapeutic process[26]. It is therefore recommended that mental health practitioners simplify routines, arrange shorter appointments and establish achievable short term goals to facilitate the individual's needs[39].

Finally, it is important to consider the propriety of various therapeutic approaches in supporting clients with FASD. For example, insight-based therapy and group therapy may not be appropriate for clients with FASD as they find it difficult to relate to other's feelings[39]. However, individual therapy that incorporates modelling, coaching, and skill-building has been identified as being of greater pertinence to this client group[26, 39]. International evidence-based interventions in the domains of parenting, attention, self-regulation and adaptive functioning have proved to be successful in supporting people with FASD[21]. Therefore, in conjunction with strategies focused on the individual, it is also important to involve the client's family, where appropriate, in order to educate them about the condition and provide them with strategies to support the individual living with FASD[40]

CONCLUSION

FASD is a growing concern in Irish society. Considering the suggested high prevalence of FASD in Ireland[4], it is likely that psychologists come into frequent contact with individuals who are impacted by the condition[31]. However, given the overlapping symptoms and co-morbidity with other psychiatric conditions, identification and assessment can be challenging, often resulting in missed diagnosis and misdiagnosis. Psychologists can play an invaluable role in a multi-disciplinary assessment and treatment of clients with FASD[26]. Thus, there is a need to increase awareness of FASD among psychologists in Ireland in order to increase the likelihood of accurate identification and diagnosis as well as creating an understanding around the various challenges and deficits faced by individuals with FASD throughout every day life[31].

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