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Why is FASD diagnosis important?

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Issue

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder resulting from prenatal alcohol exposure (PAE). Individuals with FASD can experience complex behavioural and intellectual problems that persist throughout the lifespan, and can become increasingly complicated, if unsupported. The need for early and accurate diagnosis is critical for improving outcomes and quality of life.

Background

FASD represents a constellation of adverse effects resulting from prenatal exposure to alcohol [1-4]. It is the leading known cause of preventable developmental disability in North America and has life-long implications. Although FASD is a permanent disability, with the implementation of early intervention strategies and supports, there is considerable potential to reduce the development of adverse consequences and associated costs [5-9]. The importance of supporting diagnosed individuals and their families throughout the lifespan is also critical to achieving and maintaining successful outcomes [10-14].

The effects of PAE are complex, multifaceted and vary by individual. These effects have been described as growth deficits, physical defects, facial abnormalities and central nervous system dysfunction, the latter of which is considered the most significant and persistent, requiring life-long supports and resources. Although FASD is the direct result of maternal consumption of alcohol during pregnancy, the contribution of other determinants of health (environment, socioeconomic status, genetics, adverse life experiences, mental and physical health) have all been extensively reviewed for their contributing role to the severity and prevalence of this condition [15]. The term FASD continues to be used as an identifier for persons affected by prenatal alcohol exposure, but with the release of the updated and revised Canadian diagnostic guidelines (currently in press), FASD will be considered an official diagnostic term.

Importance and Implications of an early FASD Diagnosis

Early diagnosis and the identification of appropriate interventions can help mitigate the onset and/or severity of adverse health and psychosocial outcomes, while also eliminating many of the direct costs associated with FASD (see *Social and Economic Cost of Fetal Alcohol Spectrum Disorder* Issue

Paper[1]). Early and accurate diagnoses provide a mechanism for entry into intervention and support services, resulting in a higher return on investment for health systems and programs [16].

Making a diagnosis of FASD may assist those living with the disability in obtaining health, education, and vocational services tailored to their unique needs. FASD is both an etiologic diagnosis (i.e. identifying the cause) and a functional diagnosis (i.e. identifying consequences). The diagnosis of FASD may also be result in identifying women who may struggle with problematic alcohol use and present an opportunity to offer meaningful support. Accurate diagnoses are also needed for identifying developmentally appropriate interventions by health, education, and social service providers. Although a FASD diagnosis is critical in the early years, it is especially important to understand the evolving neurodevelopmental and neuropsychiatric presentations. In particular, this understanding can be crucial for providing assistance during transition times such as entry into primary school, intermediate and high school and when transitioning into adult life and adult services.

Impact of Diagnosis For Adults

Although early diagnosis of FASD is associated with fewer adverse outcomes later in life [6], a diagnosis during adulthood can also be beneficial to the individual, their family, and the community. At present, adults in Canada have much more limited access to diagnostic services than do children and youth. Diagnosis at any age leads to a better understanding of both the individual's strengths and areas of challenge. This can help identify the strengths upon which to build and support, as well as, acceptance of more realistic goals and expectations in other areas. It is also critical to the development of a healthy self-image when individuals can identify as a person with a disability. Adults with FASD frequently require supports to maintain work and housing, financial assistance, specialized treatment for mental health issues, and assistance with a variety of daily living tasks. Access to these types of supports can be dependent on a diagnosis of disability, and in the absence of diagnosis, services for persons with FASD and their families may be unavailable or withheld [6, 17].

Impact of Diagnosis for Infants and Young Children

While more challenging, it is possible to accurately diagnose infants and young children with FASD. Several common characteristics of FASD in infants include difficult temperament [18], problems with irritability, crying, sleeping and eating [19], poor state regulation [20], blunted pain responses [21], poor visual acuity [22], and general developmental and communication delays [23]. These characteristics should be documented and monitored because assessment tools are not always accurate for children under 4 years, and some of the neurodevelopmental deficits associated with FASD can be difficult to detect at a young age [24]. While a "wait and see" approach may sometimes be prudent in the early years, early and ongoing screening to identify potential areas of neurodevelopmental delay or differences will assist parents, caregivers, and professionals supporting the child to promote optimal development and prevent secondary disabilities.

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[1] http://www.canfasd.ca/wp-content/uploads/2014/01/IssuePaper_CostFASD-Final.pdf

Recommendations

- People of all ages can benefit from an assessment for an diagnosis of FASD. Referral of individuals (across the lifespan) for an FASD assessment should be made whenever there is evidence of or suspected prenatal alcohol exposure at levels associated with physical, developmental, or behavioural effects.

- Strengthening and/or increasing access to screening and diagnostic services is crucial in order to enhance opportunities for earlier intervention. There might be need to share best practices regarding the establishment of mobile diagnostic clinics in rural areas or in regions without a resident diagnostic team to eliminate or reduce geographic barriers and long waitlists. Engaging policy makers to establish referral processes and criteria across different systems (health care, education, social services, etc.) to optimize referrals for FASD diagnosis is critical to this effort.

- The diagnostic criteria for FASD are the same for adults as for younger individuals. The length and structure of the assessment must accommodate the individual's needs and capacity to participate fully in the process. The recommendations following the diagnostic assessment must address basic and immediate needs of the client, and assist them in accessing the supports and services they need. There may be markers during an individual's lifespan when assessments should be updated, particularly the neuropsychological components.

- Parents, caregivers, and others supporting an individual with a suspected FASD be should be empowered to participate in the diagnostic process whenever possible, and in care planning activities which result. Supporting family involvement will allow clinicians to obtain more complete information being that can facilitate and strengthen the assessment process, and will prepare them for their role in assisting their loved ones following a diagnosis. Families and caregivers also play an active and invaluable role in assisting children, youth, and adults with suspected FASD to complete the numerous components of the diagnostic process.

- The diagnosis of FASD should include meaningful opportunities to reach out to birth mothers who may be struggling with alcohol and/or other substance use problems and who may be in need of care for themselves. The diagnosis of FASD in and of itself should never be taken as evidence that a child is being abused or neglected in the absence of any other typical indicators of a child protection concern. Biological parents accompanying their young or adult children must be made to feel welcome and valued as key members of their child's support team.

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