

Stigma, Discrimination and Fetal Alcohol Spectrum Disorder

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Issue:

The stigma associated with problematic alcohol use, particularly among pregnant women, presents a significant barrier to accessing medical treatment, services and supports. Individuals affected by Fetal Alcohol Spectrum Disorder (FASD), as well as their families and caregivers, can also experience stigma.

Background:

FASD is an umbrella term that is used to describe a range of disability and diagnoses that can result from prenatal alcohol exposure. It is the leading known cause of preventable developmental disability among Canadian children.

‘Stigma’, defined as a “negative stereotype” [1], has important implications for public awareness, policy and treatment practices as they relate to pregnant women who consume alcohol and individuals affected by FASD and their caregivers. In fact, many people affected by FASD, as well as pregnant women who drink alcohol, feel judged by others, which prevents them from seeking services and interventions that would contribute to an improved quality of life. While *stigma* is the negative stereotype, *discrimination* is the behaviour that results [1].

Alcohol, Pregnancy & Stigma

Alcohol use itself can be stigmatizing, as people often judge those who are unable to address their problematic alcohol use. Women who use drugs are more heavily stigmatized than their male counterparts, and pregnant women who drink alcohol often experience judgmental attitudes from service providers, feelings of shame, depression, low self esteem and fear of losing their children [2]. This stigmatization makes them generally reluctant to “emerge from the shadows” and seek help for their problems. Even when they do, they tend to face significant barriers to obtaining appropriate medical and obstetrical services that range from misinformation to denial and even inaction on the part of healthcare professionals [3].

Caregivers & Stigma

Parenting a child with a disability can be extremely exhausting for caregivers. Perceived stigma has been positively associated with emotional distress for mothers who care for children with disabilities [4]. Although society does not always recognize the benefits of raising a child with disabilities, parents report many positive experiences and value the role they play in meeting their children's diverse needs. Interestingly, in situations where mothers experience persistent chronic distress, the cause is not related to the severity of their child's disability, but instead to the perception that individuals with disabilities are stigmatized by others in the community [4]. These sentiments have significant implications on how communities view individuals with FASD and their caregivers; and these misconceptions can adversely affect their quality of life and their ability to access health-related services and resources.

Individuals with FASD & Stigma

Individuals with FASD also experience stigma. Because FASD is largely an invisible disability (i.e., no outward physical signs), society may not understand that it is a lifelong disability, which negatively impacts these individuals' ability to fit social norms and become contributing members of society. Many individuals with FASD also have mental health issues [5]. Stigma and discrimination continue to be a reality in the lives of people suffering from mental illness and have been reported to be among the greatest barriers to regaining a normal and healthy lifestyle. Stigma is emerging as an important clinical risk factor because it delays treatment seeking, worsens course and outcome, reduces compliance, and increases the risk of relapse [6]. This in turn can lead to further disability, discrimination and isolation. Due to the fact that stigma and associated discriminatory behaviours are learned from infancy onward, changes to school curriculums may be an important step towards affecting a cultural shift. Thus, a goal for improved FASD awareness, early interventions and treatment must include the identification and reduction of stigma and discrimination.

Recommendations:

- Work toward a general understanding that substance dependence, including alcohol, is a chronic, relapsing disease that should be evaluated and treated in the same way as any other chronic disease.
- Support evidence-based approaches to enable pregnant women to address their alcohol use.
- Provide appropriate training and education for service providers working in the FASD field to better support individuals with FASD and their families.
- Facilitate additional research to further explore the relationship between stigma and FASD to inform effective practices, policies and approaches around issues related to alcohol use during pregnancy.
- Continue to educate the public, including teachers, employers, service providers and communities, about FASD with special attention to respectfulness, inclusivity and acceptance.

- Stress the importance of and integrate strategies for parents/teachers to talk to their children/students about individuals with disabilities. Incorporate this messaging into different into parenting magazines and other literature, classes, school curriculums, media and social media to foster understanding, respect and acceptance.
- Work together with organizations concerned with addictions and disabilities to eradicate stigma and discrimination.

References:

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