Fetal Alcohol Spectrum Disorders (FASDs): Qualitative Familial and Clinician Perspectives

Paul J. Holdefer, M.P.H. Candidate, 2022-2023 Public Health ILEND Trainee

Research Mentor and other collaborators:
Will Story, Ph.D., M.P.H. (Core Faculty Research Mentor)
Nathan DePuy, Ph.D. Candidate (Research Advisor)

Objective:

Fetal Alcohol Spectrum Disorders (FASDs) are a class of neurocognitive disabilities caused by alcohol consumption during pregnancy (Centers for Disease Control and Prevention, 2023). In contrast to many neurological and cognitive disabilities, FASD is entirely preventable (National Institutes of Health, 2022). It is in part due to this preventative aspect of FASD that the disorder itself carries immense stigma, both for biological mothers and children with FASD (Bell et al., 2015; Zizzo & Racine, 2017). The purpose of this study was to qualitatively assess the following aspects of FASD from both the familial and clinician vantage points: knowledge of FASD; perceived assets and challenges associated with FASD; needs and recommendations regarding FASD treatment; and to elucidate what FASD stigma looks and feels like.

Method:

Neurotypical individuals who were either a family member with an immediate relation to a person with FASD (n= 4) or living with FASD themselves (n= 1) were included in analyses, as were specialty clinicians who treated and interfaced with children and families who have FASD (n= 3). This yielded a total analytic sample of 8 individuals across 7 interviews. Interviewees were recruited via snowball sampling through email communication within the author's personal and professional networks. Interview length ranged from 12:33 minutes to 36:55 minutes with an average length of 26:08 minutes. All interviews were conducted in February 2023. Qualitative, semi-structured interviews containing 9 questions each were crafted separately for both family members and clinicians and were conducted over Zoom. The interviews were audio recorded, transcribed verbatim, and analyzed in Atlas.ti qualitative analysis software (Atlas.ti 22 Windows, 2022). An iterative thematic analytic method was employed utilizing both an inductive and deductive coding approach to elicit commonalities and differences among participant responses.

Results:

All interview questions were derived from 4 overarching research questions among both families and clinicians: 1) What comprises the knowledge and perceptions of FASD?; 2) What are families' strengths and challenges?; 3) What are the recommendations and needs regarding FASD among families and clinicians?; and 4) What does FASD stigma look and/or feel like from both families' and clinicians' perspectives? Overall, family members and clinicians alike were highly knowledgeable of FASD, drawing both from personal experience and biomedical knowledge. In light of immense challenges such as navigating adversarial school systems and a lack of available specialty services, family members and clinicians similarly highlighted several

inherent skills and strengths of persons with FASD. The greatest areas of need emphasized by family members and clinicians overwhelmingly centered on providing more services specifically tailored to persons with FASD, as well as increasing societal and clinician knowledge of FASD in order to reduce stigma. FASD stigma was perceived both as overt and covert and was mentioned as a barrier to investments in research and service provision.

Conclusions:
Findings have implications for policymakers and disability advocates, placing emphasis on expanding FASD-specific services and for public and clinician education campaigns to promote empathy and understanding for persons and families with FASD.

References:

Atlas.ti Scientific Software Development GmbH [Atlas.ti 22 Windows]. (2022). Retrieved from https://atlasti.com

Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., N. Reynolds, J., & Racine, E. (2016). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. Public Health Ethics, 9(1), 65-77. https://doi.org/10.1093/phe/phv012

Centers for Disease Control and Prevention. (2023). Fetal Alcohol Spectrum Disorders (FASDs). Retrieved from https://www.cdc.gov/ncbddd/fasd/index.html

National Institutes of Health. (2022). Fetal Alcohol Spectrum Disorders. Retrieved from https://www.niaaa.nih.gov/research/fetal-alcohol-spectrum-disorders

Zizzo, N., & Racine, E. (2017). Ethical challenges in FASD prevention: Scientific uncertainty, stigma, and respect for women's autonomy. Canadian Journal of Public Health, 108(4), 414-417. https://doi.org/10.17269/CJPH.108.6048