

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

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

Introduction

Background: 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).

Overarching research questions:

1. What comprises the knowledge and perceptions of FASD?
2. What are families' strengths and challenges?
3. What are recommendations and needs regarding FASD?
4. What does FASD stigma look and/or feel like?

Methods

Semi-structured qualitative interviews were conducted with:

- 4 family members of persons with FASD
- 1 adult living with FASD
- 3 clinicians who interface with the FASD population

Average interview length was 26:08 minutes. Interviews were qualitatively thematically analyzed using an iterative inductive and deductive coding approach. Interviews were transcribed verbatim by the author. Coding and analyses were performed in Atlas.ti qualitative software (Atlas.ti 22 Windows, 2022).

Results

What comprises the knowledge and perceptions of FASD?: Family members and clinicians had both strong biomedical and lived experience knowledge of FASD.

What are families' strengths and challenges?: Parenting emerged as both a strength and a challenge among families as well as interfacing with school systems and identifying and coordinating care services.

What are recommendations and needs regarding FASD?: Overwhelmingly, families emphasized the desire for more availability and tailoring of specialty services for persons with FASD. Additionally, both families and clinicians highlighted a desire for broader knowledge and advocacy of FASD.

What does FASD stigma look and/or feel like?: Stigma of FASD was described both as direct and indirect, as well as stymying research and service investments.

Illustrative Quotes

Family Interviewee: "It's useless to try to get them to be where the neurotypicals are at because their brains are not structured that way and will not be structured that way."

Clinician Interviewee: "I would want them to know that I don't look at alcohol exposure in utero with a stigma."

Family Interviewee: "So it's this constant thing of trying to advocate for [child] and figure it out on our own. It's not like we have a navigator doing it, it's us just trying to find these things ourselves."

Family Interviewee: "And in my eyes, honestly, it's a gift. I don't think if I didn't have FAS[D], I wouldn't necessarily have the creativity I would have, or the personality that I have now today, you know?"

Conclusions & Recommendations

- FASD is perceived both through biomedical and experiential lenses.
- Despite challenges identified in parenting, working with schools, and coordinating what services are available, persons with FASD possess unique and diverse strengths.
- Needs are highly centered around available and specific services, as well as increasing societal and clinical knowledge of FASD.
- FASD stigma is both overt and covert, and at a systemic level, a barrier to further investments in FASD research and treatment.

These findings have implications for policymakers, clinicians, and disability advocates, placing emphasis on expanding FASD-specific services and for public and clinical education campaigns to promote empathy and understanding for persons and families with FASD.

References

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