

Fetal Alcohol Spectrum Disorder (FASD): Clinical Profiles and Service Utilization

PSYC513: Research Proposal

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Fetal Alcohol Spectrum Disorder (FASD)

- Range of physical and neurodevelopmental problems related to prenatal alcohol exposure
- No cure but can be managed via environmental supports and behavioural interventions
- A leading cause of developmental disability in Canada with estimates as high as 9/1000 live births
- Estimated costs of up to \$4 billion / year in Canada

Fetal Alcohol Syndrome (FAS)

- Most severe subtype of FASD
 - Only diagnosis recognized by the ICD-10
- Prevalence rate estimates as high as 2/1000 live births
- Characterized by:
 - Growth deficiencies
 - FAS facial characteristics
 - CNS damage (structural/neurological/functional)
 - Confirmed prenatal alcohol exposure

Study Goals

- Establish a basic clinical profile for the average individual with FAS that accesses services with VIHA
- Establish a basic service access profile for the average individual with FAS
- Determine which services have the most impact in reducing health, behavioural, and other issues
- Determine the timing of services that provide the most impact in reducing health, behavioural, and other issues

Study Questions

- What services / interventions lead to reductions in behavioural / psychological concerns in the clinical profiles of those diagnosed with FAS?
- Do specific clinical profile observations predict the type of services accessed by those with FAS?
- Does the timing of these services change how effective they are?
- Are there different classes of individuals with FAS that respond differentially to service access?

Cohort / Data Selection

- All those within the VIHA EHR that have been diagnosed with FAS (ICD Code: Q86.0)
 - According to Stan, n = 267
- All ages / genders
- Service access data
- Clinical report data

Phase 1: Descriptives

- Explore average clinical profile
 - What are they like?
 - What are the most common clinical concerns?
 - Do they change over time?
- Explore average service access profile
 - What services do they access the most?
 - General trends in service access?

Phase 2: MLM vs. SEM?

- What services / interventions lead to reductions in behavioural / psychological concerns in the clinical profiles of those diagnosed with FAS?
- Do specific clinical profile observations predict the type of services accessed by those with FAS?
- Does the timing of these services change how effective they are?
- Are there different classes of individuals with FAS that respond differentially to service access?

Outcomes / Products

- Give healthcare providers an idea of the needs of the population they are caring for
- Lead to streamlining of services provided to individuals with FAS as a whole
- Tailor provision of services to individuals with FAS based on their needs

Data Management

- Data will be drawn from the VIHA data warehouse
 - Housed in a 256-bit AES encrypted USB drive
 - Accessed on my own personal laptop
- Impractical / impossible to gain consent from every individual
 - Data extracted from the data warehouse must be de-identified
 - Safe Harbor de-identification method

Data Retention

- Data will be retained for the longest period of time outlined by UVic, VIHA, and TCP-2.

Questions?