

SECONDARY DISABILITIES AMONG ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDER IN BRITISH COLUMBIA

Erica Clark MSc,¹ Jan Lutke,² Patricia Minnes PhD,³ H el ene Ouellette-Kuntz MSc⁴

¹Department of Public Health & Community Services, City of Hamilton; ²Connections, The Society Serving Adults with FASD; ³Department of Psychology, Queen's University; ⁴Department of Community Health & Epidemiology, Queen's University, Ontario

ABSTRACT

Background

Adults with fetal alcohol spectrum disorder (FASD) face serious challenges because of physical, cognitive and behavioural deficits. The interaction of behavioural and mental health problems with adverse environments leads to further problems, such as trouble with the law, called "secondary disabilities". Although FASD affects about 1% of the population in the United States, very little research has been done to describe adults with FASD in Canada and what factors may affect the rate of secondary disabilities.

Objective

To determine the prevalence of secondary disabilities among adults with FASD living in the lower mainland, Okanogan Valley and West Kootenay regions of British Columbia and what factors may affect the rates of secondary disabilities.

Methods

62 adults with FASD (clients), selected as a convenience sample, identified a caregiver who completed a structured interview and self-administered survey. The magnitude of association was calculated with odds ratios.

Results

The clients were found to have high rates of secondary disabilities. Four variables were associated with lower rates of secondary disability: age under 20 years, living with a caregiver, requiring a minimal to low level of support, and not being vulnerable to manipulation.

Conclusions

The prevalence of secondary disabilities among adults with FASD living in the lower mainland, Okanogan Valley and West Kootenay regions of British Columbia are at least as high as the prevalence found in the Seattle Longitudinal Study on Alcohol and Pregnancy. The prevalence of secondary disabilities may be affected by age, living with a caregiver, adaptive functioning and vulnerability to manipulation.

Key words: fetal alcohol spectrum disorder, secondary disabilities, adults

Fetal alcohol spectrum disorder (FASD), which includes fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol related neurodevelopmental disorder (ARND) and alcohol related birth defects (ARBD), is one of the leading known causes of mental retardation in North America,² though it is estimated that only about 50% of those with FASD meet the

current definition of mental retardation.³ FASD is caused by prenatal alcohol exposure and is characterized by a distinctive facial dysmorphism, growth retardation, neurological deficits and behavioural problems.⁴

Diagnosis of FAS or alcohol related effects is most accurately done between ages 2 and 11 years.⁴ After about 11 years of age diagnosis

may not be possible or may only be possible with a skilled clinician experienced in adult and youth diagnosis. After puberty growth catch up is common and the facial morphology changes.⁵ A history of prenatal alcohol exposure, necessary for a diagnosis of pFAS, ARND or ARBD may be difficult or impossible to obtain.

Much of the research on FASD has focused on etiology, prevention and the diagnosis and assessment of children. A few longitudinal studies in the United States, France, Germany and Sweden^{3,6,7,8,9} have looked at the effects of FASD and found serious lifelong consequences manifested as physical, cognitive and behavioural deficits.²

Research from the Seattle Longitudinal Study on Alcohol and Pregnancy identified a number of problems coined “secondary disabilities” among youth and adults with FASD. These secondary disabilities, listed below, were hypothesized to be the result of the interaction of behavioural and mental health problems with adverse environments.³ They include:

1. mental health problems,
2. disrupted school experience (suspension, expulsion or dropping out),
3. trouble with the law (ever been in trouble with the authorities, charged or convicted of a crime),
4. confinement (inpatient treatment for mental health or drug/alcohol problems or incarceration for a crime),
5. inappropriate sexual behaviour,
6. alcohol/drug problems,
7. problems with employments,
8. dependent living, and
9. problems with parenting.

These findings were confirmed by other longitudinal studies in France, Germany and Sweden.^{3,6,7,8,9,10}

The 1996 study by Streissguth, Barr, Kogan and Bookstein³ examined risk and protective factors that were thought to influence the occurrence of secondary disabilities. Being male and/or older than 12 years increased the likelihood of disruptive school experience, trouble with the law, confinement (in a hospital or prison) and dependent living.

Eight factors were found to decrease the likelihood of nearly all the secondary disabilities. From strongest to weakest, these “universal” protective factors were; living in a stable and nurturing home for over 72% of life, being diagnosed before the age of 6 years, never having experienced violence against oneself, staying in each living situation for an average of more than 2.8 years, experiencing a good quality home from age 8 to 12 years, having applied for and been found eligible for supports from the Division of Developmental Disabilities,[‡] having a diagnosis of FAS (rather than FAE), and having basic needs met for at least 13% of life. These findings suggest that with appropriate interventions, it may be possible to reduce the rate of secondary disabilities among those with FASD.

Within Canada there has been far less research on FASD and the extent of secondary disabilities, and the potential impact of differences in the Canadian health and social services systems is unknown. Would Canada have similar rates to the United States? Also, very little demographic information is available to describe adults with FASD living in Canada.

This study utilized a cross-sectional survey design with a convenience sample to determine the demographic and secondary disabilities profile of adults with FASD living in the lower mainland, Okanogan and West Kootenay regions of British Columbia. British Columbia was chosen as it is one of two provinces where adults can be diagnosed by two existing pediatric comprehensive assessment teams resulting in a larger population of adults diagnosed with FAS or alcohol related effects.

METHODS

This paper is part of a larger research project described elsewhere.¹¹ Ethics approval for this study was obtained from the Queen’s University Faculty of Health Sciences Research Ethics Board. Study participants

[‡] Community living services in Washington State, that includes case managers, job placement, job coaching, and shelter.

were recruited during the spring and summer of 2002 through the FAS/E Support Network of British Columbia.

There were two categories of participants in this study. The first category consisted of adults with FASD, hereafter referred to as “clients.” The second category included friends, family members or support workers identified by adults with FASD to provide information for the study, hereafter referred to as “caregivers.”

All individuals 17 years of age and older who were known to the FAS/E Support Network of British Columbia and had a diagnosis of fetal alcohol syndrome, probable fetal alcohol syndrome, partial fetal alcohol syndrome, fetal alcohol effects, probable fetal alcohol effects, alcohol related birth defects or alcohol related neurodevelopmental disorder were identified as potential participants. The lower age limit of 17 years was chosen as the FAS/E Support Network identified it as the age when the transition out of child and youth services began. The FAS/E Support Network identified 175 potential participants, of which 113 were eligible to participate. Reasons for exclusion included: unable to locate (n=25), institutionalized (prison or psychiatric) (n=17), and deemed unable to participate (n=20).

For each client participant, a caregiver completed a written survey and a telephone interview. The written survey contained questions on demographic characteristics and the presence or absence of a number of secondary disabilities. The telephone interview consisted of the Functional Assessment.

Functional assessment

The Functional Assessment,¹² a tool used by the British Columbia Ministry of Children and Family Development to assess level of care needed by an individual, was used as a proxy measure for the level of adaptive functioning among clients. It has the advantage of being applicable to all levels of IQ and age and may be completed by someone who is not a trained psychologist.

However, at the time of this study no reliability or validity testing had been done on the tool. Since the Functional Assessment

reports the level of care required for an individual rather than adaptive behaviour, a high level of care required corresponds to a low level of skill in adaptive behaviour.

The complete list of domains and sub domains examined by the Functional Assessment is shown below. Examples of abilities examined are listed for each sub-domain.

Functional assessment domains, sub domains and sample items

A. Personal care

1. Toileting

- Four items including “Recognizes/ indicates need to go to toilet” and “Flushes toilet after use.”

2. Personal hygiene

- Five items including “Washes hands and face” and “Takes care of personal hygiene – body odor, nails, combing hair, (women) menstruation, (men) shaving.”

3. Eating

- Five items including “Uses table utensils” and “Has general table manners – says “please” and “thank you”, uses Napkin, doesn’t talk with mouth full.”

4. Dressing

- Five items including “Dresses and undresses at appropriate time” and “Does fasteners – buttons, zippers, snaps.”

B. Daily living skills

1. Room management

- Five items including “Keeps room tidy and/or accepts sharing of responsibility of room cleaning” and “Takes care of personal belongings.”

2. Kitchen skills

- Five items including “Sets table – dishes, glasses, cutlery, clears after meal” and “ Puts away groceries, linens, dishes in appropriate place.”

3. Domestic skills

- Five items including “Does minor household tasks – dusting, sweeping, tidying” and “Takes an interest in how house looks – pictures, plants, furniture arrangement.”

4. Telephoning

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

- Five items including “Understands the function of a telephone” and “Takes telephone messages.”

5. Time

- Five items including “Understands the purpose of a clock” and “Tells time.”

6. Health concerns

- Five items including “Knows when he/she is ill and can indicate illness to others” and “Makes doctors and dental appointments.”

C. Community access

1. Transportation

- Five items including “Is familiar with the neighbourhood and the services available” and “Behaves appropriately when using public transportation.”

2. Money

- Five items including “Understands function of money” and “Uses banking facilities.”

3. Shopping

- Five items including “Goes on errands” and “Can get assistance from store clerk.”

4. Leisure/ recreation

- Five items including “Takes part in planned/ supervised leisure” and “Satisfied with his own use of leisure time.”

5. Pre-vocational

- Five items including “Follows instructions” and “Makes decisions or choices.”

D. Social skills

1. Communication

- Five items including “Knows what to do if lost – name, address, phone number” and “Asks for assistance or information when needs it.”

2. Awareness of others

- Five items including “Smiles and greets people he/she recognizes” and “Is not overly friendly with strangers.”

3. Interpersonal skills

- Five items including “Makes friends” and “Shares with others but sets limits.”

4. Problem solving

- Five items including “Knows what happens when he/she does well or when rules are broken” and “Can work through a decision when given two choices.”

E. Maladaptive behavior

1. Antisocial behavior

- Five items including “Lies or cheats” and “Takes others’ property without permission.”

2. Rebellious behavior

- Five items including “Ignores regulations or regular routines” and “Misbehaves in group settings.”

3. Stereotyped behavior and odd mannerisms

- Five items including “Has stereotyped behaviors – rocks, twirls objects, paces” and “Tears off clothing.”

4. Psychological disturbances

- Five items including “Has hypochondriachal tendencies” and “Demands excessive attention.”

5. Violent and destructive

- Five items including “Threatens or does physical violence to others” and “Has violent temper or temper tantrums.”

6. Inappropriate sexual behavior

- Five items including “Engages in masturbation or sexual intercourse in inappropriate places or times” and “Has tendency to direct sexual activity towards inappropriate others – unwilling partners, children.”

7. Self-abusive behavior

- Six items including “Bites self” and “Bangs head or other part of body against objects.”

F. Health and physical care demands

- Five items including “Epilepsy” and “Diet”

Once collected, the information was entered and managed in password protected EXCEL files. Statistical analyses were performed using SPSS for Windows Version 11.0. The magnitude and range (using a 95% confidence interval) of the association between the prevalence of secondary disabilities and demographic and clinical characteristics was calculated with odds ratios.

RESULTS

The majority of eligible clients agreed to be contacted by the student researcher (first author) (77.9%) and 78.4% of those contacted consented to participate in the study. The total number of clients who participated in the study was 62, yielding a participation rate of

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

55%. As shown in Table 1, most were diagnosed with either FAS or FAE (45% and 39% respectively for clients).

The study participants were more likely to have some form of support, either disability benefits or some other support service, than those who did not participate or were

excluded. The types of support services received included supported living services, which ranged from help with household chores to living in a group home, assisted employment and support due to a co-morbid diagnosis or involvement of the justice department.

TABLE 1 General characteristics of participants, non-participants and ineligible

Characteristic	Participants (n)	Non-participants (n)	Excluded (n)
Mean age (range)	22 (17-43 years)	25 (17-60 years)	28 (17-44 years)
Gender			
Male	42% (26)	61% (32)	45% (28)
Female	58% (36)	39% (20)	55% (34)
Mean age diagnosed (range)	9 (1-41 years)	13 (0.02-50 years)	13 (0-26 years)
Receive disability benefits	44% (27)	24% (12)	16% (10)
Currently receive support services	26% (16)	0 ^a	0
Diagnosis			
Fetal alcohol syndrome	45% (28)	67% (35)	61% (38)
Fetal alcohol effects	45% (28)	0 ^b	0
Probable fetal alcohol syndrome	10% (6)	20% (10)	24% (15)
Probable fetal alcohol effects	0 ^c	0	0
Unknown ^d	0	13% (7)	15% (9)
Ethnicity			
Caucasian	42% (26)	47% (24)	24% (15)
Aboriginal	39% (24)	22% (11)	45% (28)
Caucasian/Aboriginal	11% (7)	0	0
Other (Asian, Thai, etc.)	8% (5)	0 ^b	0 ^b
Unknown	0	33% (17)	27% (19)

Note: there were a total of 62 participants, 51 non-participants, and 62 excluded

^a number too low to report

^b number too low to report; combined with "unknown" category

^c number too low to report; combined with "Fetal alcohol effects" category

^d individuals known to the staff of the FAS/E Support Network but unable to confirm what the diagnosis were

As shown in Table 2, 92% of the clients were described by their caregivers as being vulnerable to manipulation. 87% of the clients had experienced some form of violence during their lives and 77% of the

clients had experienced either physical and/or sexual abuse.

Only 34% of the clients studied had an IQ score below 70 although the majority of the clients required a moderate to high level

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

of care. The average IQ score of the clients was 76 with a range of 45 to 120. The average IQ of the clients receiving disability benefits was 70 with a range of 47 to 84. The most common secondary disabilities ever experienced by the clients were mental health diagnosis (92%) and disruptive school experience (61%).

The most common mental health diagnosis among clients was attention deficit

disorder/attention deficit hyperactivity disorder (65%) followed by depression (47%) and panic disorder (21%). Some of the other diagnoses listed included post traumatic stress disorder, obsessive compulsive disorder, oppositional defiance disorder and bipolar disorder.

TABLE 2 Profile of clients as reported by the caregivers, N=62.

Independent variable	Frequency	Percent
< 20 years old	23	37
Living with a caregiver	43	69
Had at least one child	16	26
Still involved in parenting (of 16 clients)	9	56
Diagnosed before age 6	21	34
Average years per household <2.9	15	24
Vulnerable to manipulation	57	92
Ever experienced violence	54	87
Verbal	50	81
Physical	43	69
Sexual	34	55
IQ ≤ 70	21	34
Functional Assessment:		
Minimal or low level of care required ^a	12	19
Moderate level of care required	23	37
High level of care required	27	44
Secondary Disability:		
Mental health diagnosis	57	92
Disruptive school experience	38	61
Trouble with the law	28	45
Displays sexually inappropriate behaviour	28	45
Ever confined to a hospital or prison	20	32
Ever had an alcohol or drug problem	22	22

^a number of participants requiring minimal level of care too low to report; combined with low level of care required

The associations between demographic and clinical characteristics and secondary

disabilities are shown in Tables 3, 4, and 5.

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

TABLE 3 Odds ratio and 95% confidence interval for two secondary disabilities, history of alcohol and drug problems and mental health diagnosis, and a number of demographic and clinical characteristics reported by caregivers

Demographic & Clinical Characteristics	Secondary Disability					
	Alcohol & drug problems			Mental health diagnosis		
	Yes (%)	No (%)	OR (95%CI)	Yes (%)	No (%)	OR (95%CI)
Under 20 years old	17.4	82.6	0.25 (0.07-0.86)	91.3	8.7	0.88 (0.14-5.67)
Under 2.9 years in each household	53.3	46.7	2.81 (0.85-9.36)	93.3	6.7	1.37 (0.14-13.27)
Male	46.2	53.8	2.23 (0.77-6.44)	96.2	3.8	3.13 (0.33-29.74)
FAS diagnosis category	38.2	61.8	1.31 (0.46-3.74)	91.2	8.8	0.79 (0.12-5.12)
Diagnosed before 6 years of age	28.6	71.4	0.64 (0.2-2.01)	95.2	4.8	2.29 (0.24-21.89)
IQ below 70	23.8	76.2	0.50 (0.14-1.79)	100.	0.0	N/A
Ethnicity Aboriginal	41.7	58.3	1.55 (0.54-4.47)	91.7	8.3	0.94 (0.15-6.10)
Living with caregiver	27.9	72.1	0.35 (0.11-1.07)	90.7	9.3	0.54 (0.06-5.20)
Adult support services	31.3	68.8	0.59 (0.17-2.14)	87.5	12.5	0.50 (0.06-3.93)
Disability pension	40.7	59.3	1.38 (0.40-4.77)	88.9	11.1	0.47 (0.05-4.92)
Minimal to low care level required	0.0	100.0	N/A	83.3	16.7	0.32 (0.05-2.17)
Vulnerable to manipulation	36.8	63.2	1.18 (0.17-17.92)	94.7	5.3	18.00 (1.84-175.78)
Ever experienced violence	37.0	63.0	1.75 (0.10-13.81)	90.7	9.3	N/A

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

TABLE 4 Odds ratios and 95% confidence interval for two secondary disabilities, confinement in a prison or psychiatric institute and trouble with the law, and a number of demographic and clinical characteristics reported by the caregivers.

Demographic & Clinical Characteristics	Secondary Disability					
	Confinement			Trouble with the law		
	Yes (%)	No (%)	OR (95%CI)	Yes (%)	No (%)	OR (95%CI)
Under 20 years old	21.7	78.3	0.44 (0.14-1.45)	38.1	61.9	0.52 (0.18-1.56)
Under 2.9 years in each household	46.7	53.3	2.15 (0.65-7.16)	66.7	33.3	2.82 (0.82-9.76)
Male	42.3	57.7	2.20 (0.74-6.50)	56.0	44.0	1.73 (0.61-4.93)
FAS diagnosis category	29.4	70.6	0.75 (0.26-2.18)	38.7	61.3	0.43 (0.15-1.25)
Diagnosed before 6 years of age	33.3	66.7	1.27 (0.41-4.00)	42.1	57.9	0.65 (0.22-1.99)
IQ below 70	33.3	66.7	1.36 (0.39-4.76)	31.6	68.4	0.33 (0.09-1.17)
Ethnicity Aboriginal	25.0	75.0	0.57 (0.18-1.78)	60.9	39.1	2.33 (0.80-6.85)
Living with caregiver	25.6	74.4	0.38 (0.12-1.18)	35.0	65.0	0.15 (0.04-0.56)
Adult support services	31.3	68.8	0.68 (0.19-2.46)	42.9	57.1	0.53 (0.15-1.93)
Disability pension	37.0	63.0	1.18 (0.34-4.12)	50.0	50.0	0.80 (0.23-2.73)
Minimal to low care level required	8.3	91.7	0.15 (0.02-1.24)	27.3	72.7	0.33 (0.08-1.40)
Vulnerable to manipulation	33.3	66.7	N/A	52.8	47.2	N/A
Ever experienced violence	35.2	64.8	N/A	50.0	50.0	1.00 (0.06-16.86)

The highest magnitude of association is reported in Table 3. Clients who were described as “vulnerable to manipulation” were 18.0 times more likely to have a mental health problem. The lowest (significant) magnitude of association was between age and a history of alcohol and drug problems (see Table 3). Clients under 20 years of age were 0.25 times less likely to have a history of alcohol and drug problems than those 20 years of age and over. In Table 4 we report the only

support significantly associated with a secondary disability; living with a caregiver was associated with a decreased likelihood of getting in trouble with the law (OR=0.15). Finally, in Table 5, requiring a minimal to low level of care was associated with a decreased prevalence of sexually inappropriate behaviour (OR=0.09). IQ below 70 was not significantly associated with any secondary disabilities; nor was ethnicity.

TABLE 5 Odds ratios and 95% confidence interval for two secondary disabilities, history of sexually inappropriate behaviour and history of disruptive school experience, and a number of demographic and clinical characteristics reported by the caregivers.

Demographic & Clinical Characteristics	Secondary Disability					
	Sexually inappropriate behaviour			Disruptive school experience		
	Yes (%)	No (%)	OR (95%CI)	Yes (%)	No (%)	OR (95%CI)
Under 20 years old	45.0	55.0	0.73 (0.24-2.19)	52.2	47.8	0.50 (0.17-1.46)
Under 2.9 years in each household	46.7	53.3	0.75 (0.23-2.47)	66.7	33.3	1.38 (0.40-4.74)
Male	36.0	64.0	0.36 (0.12-1.06)	69.2	30.8	1.69 (0.58-4.91)
FAS diagnosis category	53.1	46.9	1.34 (0.46-3.87)	60.6	39.4	0.85 (0.30-2.42)
Diagnosed before 6 years of age	47.6	52.4	0.97 (0.32-2.89)	61.9	38.1	1.02 (0.34-3.03)
IQ below 70	70.0	30.0	3.37 (0.94-12.12)	50.0	50.0	0.53 (0.16-1.74)
Ethnicity Aboriginal	45.5	54.5	0.74 (0.25-2.17)	62.5	37.5	1.01 (0.35-2.93)
Living with caregiver	46.2	53.8	0.60 (0.19-1.90)	54.8	45.2	0.32 (0.09-1.14)
Adult support services	57.1	42.9	1.44 (0.39-5.27)	62.5	37.5	0.75 (0.21-2.70)
Disability pension	60.9	39.1	1.75 (0.49-6.22)	65.4	34.6	0.94 (0.27-3.36)
Minimal to low care level required	11.1	88.9	0.09 (0.01-0.80)	50.0	50.0	0.53 (0.15-1.90)
Vulnerable to manipulation	51.0	49.0	3.12 (0.30-32.03)	66.1	33.9	5.84 (0.57-60.04)
Ever experienced violence	51.0	49.0	N/A	60.4	39.6	0.00

DISCUSSION

Demographic and clinical characteristics

Several characteristics emerged as key features of the clients in this study. They tended to be of average intelligence (average IQ was 76) but required high levels of support; they were

vulnerable to manipulation; had at least one mental health diagnosis and most were exposed to physical, sexual and/or verbal violence. It is reasonable to suggest that there may be a high degree of correlation between these, and other, variables; however, limited sample size did not permit extensive testing of inter-correlation.

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

Within British Columbia, the requirements for community living support services are: a measured IQ of 70 or lower with onset prior to age 18 and adaptive skills deficits in two or more areas. Only 34% of the clients had an IQ below 70 but 81% required a moderate to high level of care indicating severe deficits in adaptive skills. Previous studies that looked at both the IQ and adaptive skills of individuals with FASD also noted the gap between IQ and adaptive skills.^{1,3} These results suggest that IQ alone is not sufficient criterion for determining the need for support services among persons with FASD as they may have great difficulty performing day-to-day activities while still possessing a measured IQ of 70 or greater.

This study had a high percentage of clients described by caregivers as “vulnerable to manipulation” (92%). Previous studies have not focused on the assessment of vulnerability to manipulation; however, this issue has been touched on in discussions of the criminal justice system and adults with intellectual disabilities. False confessions, acquiescence, difficulty understanding simplified cautions and consent have all been identified as issues that are affected by vulnerability to manipulation and therefore require further consideration.^{13,14,15}

The proportion that had ever experienced verbal, physical and/or sexual abuse was high at 87%. In the 1996 report by Streissguth and colleagues³, the prevalence of domestic, physical and/or sexual violence was 72% for adolescents and adults with FASD. When verbal abuse was excluded from the results of our study, the resulting prevalence was 77%, similar to what was found previously. Research suggests that maltreatment of children with mild disabilities can be associated with a lack of understanding of what these children can achieve.¹⁶ As better information about FASD and the limitations faced by individuals becomes available and is widely disseminated the unacceptably high rate of maltreatment in this population may decrease.

Secondary disabilities

Although it is not possible to make a direct comparison to the prevalence of secondary disabilities found in the studies done in the United States, France and Germany, the results of our

study are similar to those from the Seattle Longitudinal Study on Alcohol and Pregnancy.

There are only two categories where it appears that there might be a difference (though not significant) and these are confinement (e.g. hospital or prison) and trouble with the law. The prevalence rates from our study were slightly lower than those found by Streissguth, Barr, Kogan and Bookstein³ but one of our exclusion criteria was confinement in a prison or psychiatric hospital. These findings would suggest that having access to a universal healthcare system or differences between the Washington State and British Columbia social services are no better or worse for adults with FASD.

The percent of clients who had at least one mental health diagnosis was extremely high at 92%, which is much higher than the prevalence of 30-40% in an intellectually disabled population¹⁷ but similar to that found by Streissguth, Barr, Kogan and Bookstein³ in a Seattle population of FASD.

There are several possible theories for the high co-morbidity including;

- 1) the susceptible genes for alcoholism and mental health problems may be the same,¹⁸
- 2) women with mental health problems, such as schizophrenia, may use alcohol as self-medication for the symptoms of the mental health problems or the side effects of the anti-psychotic medications,¹⁹
- 3) the mental health problems (e.g. ADHD) may actually be a component of FASD and not a separate diagnosis^{20,21} and,
- 4) the lack of support and understanding given to adults with FASD likely contributes to an increased prevalence of mental health problems such as depression (this theory is considered for those with functional psychotic illness by Phillips & Johnson¹⁹).

At this time there is insufficient evidence to determine what the nature of the relationship between mental health problems and FASD or mental health problems and substance misuse is. Living with a caregiver is a key resource for individuals with FASD. Our study revealed that it was significantly associated with not getting into trouble with the law (OR=0.15).

One of the four significant findings in this study involved the association between requiring a

minimal to low level of care and history of sexually inappropriate behaviour (OR=0.09).

It is noteworthy that none of the secondary disabilities were significantly associated with an IQ below 70, which is required for a classification of mental retardation. This finding is in agreement with previous research that indicated mental retardation, or perhaps more specifically, a measured IQ below 70, is not the primary manifestation of FASD.

Strengths and limitations

The key strength of this study is the descriptive information it provided. This represents the first study to provide prevalence data on demographic characteristics and secondary disabilities for a population of adults with FASD living in Canada. The limitations of this study are related to its design. Only 35% of the 175 identified as potential clients were interviewed, partly due to the constraints of the first author related to completing a master's degree.

Had more time been available for data collection more of the potential clients could have been located. Personal safety expectations of Queen's University were a factor in excluding several of those "deemed unable to participate." Although this weakens the validity of the results, it is likely that the prevalence of secondary disabilities would be higher amongst those excluded as one or more of the secondary disabilities, such as confinement or inappropriate sexual behaviour, may have been a factor in the decision to exclude.

Since one of the exclusion criteria for the adults with FASD was not having a caregiver the generalizability to those not receiving any form of support may be affected. The prevalence of secondary disabilities among adults not receiving any form of support may be higher than what was found in this study. Due to the living arrangement of many of the clients, it was not possible to have 62 different caregivers participating in the study. Also, as this was a cross-sectional study, it was not possible to draw definitive conclusions about the cause of the associations noted.

Due to a lack of satisfactory screening tools, there is no screening for FASD taking place in Canada.²² This has led to a bias in the individuals who are diagnosed with FAS or alcohol related

effects and therefore the individuals eligible for inclusion in this study.

Habbick et al.²³ estimated that the prevalence of fetal alcohol effects (now alcohol related effects) was four times that of FAS but in this study the ratio was nearly one to one indicating that there was likely a bias in the selection of clients. Streissguth, Barr, Kogan and Bookstein³ found that a diagnosis of FAS rather than FAE was protective for all of the secondary disabilities except mental health problems. Therefore, the selection bias of this study likely resulted in an underestimate of the true prevalence of secondary disabilities in the population of adults with FASD living in British Columbia.

CONCLUSION

From this preliminary study it can be concluded that adults with FASD in British Columbia experience rates of secondary disabilities at least as high as those in the Seattle Longitudinal Study on Alcohol and Pregnancy. Cognitive deficits (IQ below 70) did not significantly alter the likelihood that clients would experience any of the secondary disabilities whereas adaptive functioning did. This has been noted in other research that indicated adaptive functioning had a greater affect on the rate of secondary disabilities than cognitive functioning and therefore is likely a better predictor of future problems.

Acknowledgements

This project was completed as part of the degree requirements for the Queen's University Department of Community Health & Epidemiology Master of Science degree for the first author. It would not have been possible to complete this project without the participation and support of the FAS/E Support Network of BC, individuals with FAS and alcohol related affects and their friends and families.

Corresponding Author: oullette@post.queensu.ca

REFERENCES

1. Streissguth A, Aase J, Clarren S, Randels S, LaDue R & Smith D. Fetal Alcohol Syndrome in adolescents and adults. *J Am Med Assoc* 1991; 265(15): 1961-1967.

Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia

2. Streissguth A & O'Malley K. Neuropsychiatric implications and long term consequences of fetal alcohol spectrum disorders. *Semin Clin Neuropsychiatry* 2000; 5: 177-190.
3. Streissguth A, Barr H, Kogan J & Bookstein F. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final report to the Centers for Disease Control and Prevention. Grant #R04/CCR008515. Seattle: University of Washington School of Medicine, 1996. (Copies can be obtained by contacting the Fetal Alcohol and Drug Unit).
4. Institute of Medicine (US). Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment. Washington DC: National Academy Press, 1996.
5. Streissguth A. A long-term perspective of FAS. *Alcohol Res Health* 1994; 18(1):74-81.
6. Aronson M: Children of alcoholic mothers: results from Göteborg, Sweden, In: *The challenges of fetal alcohol syndrome: overcoming secondary disabilities* (Streissguth A & Kanter J ed), University of Washington Press, Seattle, pp15-24, 1997.
7. Lemoine P & Lemoine P. Avenir des enfants de mères alcooliques (Étude si 105 cas retrouvés à l'âge adulte) et quelques constatations d'intérêt prophylactique. *Ann Pediatr* 1992; 39:226-235.
8. Spohr H: Fetal alcohol syndrome in adolescence: long-term perspective of children diagnosed in infancy, In: *Alcohol, pregnancy, and the developing child* (Spohr H & Steinhausen H ed), Cambridge University Press, Cambridge, pp 207-226, 1996.
9. Steinhausen H. Psychopathology and cognitive functioning in children with fetal alcohol syndrome. In: Spohr, H., Steinhausen, H., editors. *Alcohol, pregnancy, and the developing child*. Cambridge: Cambridge University Press; 1996. p. 227-248.
10. Löser H, Bierstedt T, & Blum A. Alkoholembyopathie im erwachsenenalter: eine langzeituntersuchung. *Dtsch Med Wochenschr* 1999; 124:412-418.
11. Clark E. Community integration and independence among adults with fetal alcohol spectrum disorder in British Columbia [dissertation]. Kingston (ON): Queen's Univ.; 2003.
12. British Columbia Ministry of Children and Family Development. 2001.
13. Beail N. Interrogative suggestibility, memory and intellectual disability. *J Appl Res Intellect Disabil* 2002; 15:129-137.
14. Lindsay W. Integration of recent reviews on offenders with intellectual disabilities. *J Appl Res Intellect Disabil* 2002; 15:111-119.
15. Linhorst D, Bennett L & McCutchen T. Development and implementation of a program for offenders with developmental disabilities. *Ment Retard* 2002; 40(1): 41-50.
16. Vig S & Kaminer R. Maltreatment and developmental disabilities in children. *J Dev Phys Disabil* 2002; 14(4):371-386.
17. Percy M, and Brown I.: Causes and contributing factors, and approaches to intervention, In: *Developmental Disabilities in Ontario First Edition* (Percy M, Brown I, ed), Front Porch Publishing, Toronto pp223-252, 1999.
18. Mueser K, Drake D & Wallach M. Dual diagnosis: a review of etiological theories. *Addict Behav* 1998; 23:717-734.
19. Phillips P & Johnson S. How does drug and alcohol misuse develop among people with psychotic illness? A literature review. *Soc Psychiatry Psychiatr Epidemiol* 2001; 36:269-276.
20. Coles C. Fetal alcohol exposure and attention: moving beyond ADHD. *Alcohol Res Health* 2001; 25(3):199-203.
21. O'Malley K & Nanson J. Clinical implications of a link between Fetal Alcohol Spectrum Disorder and Attention-Deficit Hyperactivity Disorder 2002; 47(4):349-354.
22. Legge C, Roberts G, & Butler M. Situational analysis: fetal alcohol syndrome/ fetal alcohol effects and the effects of other substance use during pregnancy. Ottawa (ON): Health Canada; 2000.
23. Habbick B, Nanson J, Snyder R, Casey R, and Schulman, A. Foetal Alcohol Syndrome in Saskatchewan: unchanged incidence in a 20-year period. *Can J Public Health* 1996; 87(3):204-207.