

Knowledge of Northern Ontario School of Medicine Students
on the Subject of Fetal Alcohol Spectrum Disorder

By

Celisse Bibr

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APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Shelley Watson
(Supervisor/Directrice de thèse)

Dr. Dana Vrjanik
(Committee member/Membre du comité)

Dr. Sylvie Laroque
(Committee member/Membre du comité)

Dr. Kaitlyn McLachlan
(External Examiner/Examineur externe)

Approved for the Faculty of Graduate Studies
Approuvé pour la Faculté des études supérieures
Dr. David Lesbarrères
Monsieur David Lesbarrères
Dean, Faculty of Graduate Studies
Doyen, Faculté des études supérieures

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Abstract

Canadian physicians report feeling unprepared regarding the diagnosis and treatment Fetal Alcohol Spectrum Disorder (FASD). This thesis investigates the knowledge that future healthcare practitioners gain during their time at the Northern Ontario School of Medicine (NOSM), as well as the advice they would give to women regarding the use of alcohol during pregnancy.

This two-phased mixed methods study included two surveys ($N=24$), and a semi-structured interview ($N=8$). Results indicate that NOSM students are unaware of the specifics of FASD and are not confident in their knowledge on the subject. Barriers to learning were identified as: (1) inconsistencies between student educational experiences; and (2) the overwhelming nature of medical education. Solutions involving enhanced opportunity for exposure, supporting experience through formal curriculum, and attaining knowledge from different sources are proposed. Through improving medical education, future physicians will be better prepared to care for individuals with FASD, thereby improving support for these individuals.

Keywords: Fetal Alcohol Spectrum Disorder, Developmental Disability, Intellectual Disability, Northern Ontario School of Medicine, medical education, healthcare education, medical school, medical students, mixed methods,

Co-Authorship Statement

Dr. Shelley Watson

Dr. Watson is the supervisor of this project, and consistently gave feedback in response to all updates she was provided with. She conducted the first interview of this study as part of my standardized training, and steered both myself and this thesis in the right direction. Dr. Watson will be listed as a co-author on the journal articles, when they are submitted for publication.

Dr. Kelly Harding

Dr. Harding completed the thesis from which this project was born. She gave her resources (such as the questionnaires, vignettes and semi-structured interview guide) to be adapted to this research question, and offered valuable feedback along the completion of this thesis. Dr. Harding will be listed as a co-author on the journal articles, when they are submitted for publication.

Dr. Sylvie Larocque

Dr. Larocque is a member of the committee that oversaw this project. Along with valuable feedback, Dr. Larocque gave her perspective on medical education, both as a professor and as a nurse, as well as her guidance regarding qualitative data analysis. Dr. Larocque will be listed as a co-author on the journal articles upon submission for publication.

Dr. Diana Urajnik

Dr. Urajnik is also a member of the committee that oversaw this project. As such, Dr. Urajnik also provided her time and feedback, as well as her own perspective as a faculty member at NOSM which was particularly beneficial during the knowledge translation process. Dr. Urajnik will be listed as a co-author on the journal articles upon submission for publication.

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Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a term that describes the range of effects of prenatal exposure to alcohol (Cook et al., 2015; Mattson, Crocker & Nguyen, 2011). FASD is the leading non-genetic cause of intellectual disability in the Western world (Cook et al., 2015; Public Health Agency of Canada [PHAC], 2005). Although there are currently no national statistics on the prevalence of FASD in Canada (Chudley et al., 2005), it has been estimated based on studies within the United States, and within smaller populations within Canada. For example, the Public Health Agency of Canada cites Sampson and colleagues' (1997) statistic of 9.1 per 1000 live births within the United States. Within Alberta, the prevalence of FASD has been reported to be approximately 11.7 (ranging from 8.2 to 15.1) per 1000 population (Thanh, Jonsson, Salmon & Sebanstianski, 2013). More recently, May and colleagues (2014) estimated the prevalence of FASD to be from 24 to 48 per 1000 children within a Midwestern United States community. In addition, Popova, Lange, Probst, Gmel and Rehm (2017) conducted a systematic review to determine the prevalence of FAS (a disorder previously under the FASD umbrella in Canada; Cook et al., 2015), and concluded that the estimated global prevalence of FASD was 4.6 per 10,000 people (95% CI 9.4–23.3). They also estimated the prevalence in Canada to be 10.5 per 10,000 people (95% CI 0.0–34.9; Popova et al., 2017). As the prevalence of FAS in those with FASD is only one in nine or 10 (Chudley, 2008), the results of Popova et al. (2017) and May et al. (2014) indicate that FASD may be even more common than previously believed.

That said, diagnosis of FASD is often delayed or not considered due to its complex nature (Chudley et al., 2005). The mechanisms through which alcohol causes cognitive deficits are numerous, complicated, and differentially activated (Goodlett, Horn & Zhou, 2005; Laufer et al., 2013; Pretrelli, Weinberg & Hicks, 2018). In addition, there is confusion as to the outcomes of

prenatal alcohol exposure, especially in low-to-moderate consumption of alcohol (Day et al., 2013; Kelly et al., 2008). As a result, a significant portion of healthcare professionals believe the effects of alcohol on the fetus to be unclear (Anderson et al., 2010; Payne et al., 2014; PHAC, 2005). Findings regarding healthcare providers, including midwives, family physicians, psychiatrists, obstetricians/gynecologists, and pediatricians, demonstrate a lack of knowledge regarding the diagnostic criteria of FASD, long term outcomes of prenatal exposure to alcohol, FASD identification, and screening tools for alcohol dependency (PHAC, 2005). Providers also report feeling unprepared to care for pregnant clients showing signs of alcohol dependency (PHAC, 2005; Tough, Clarke, Hicks & Clarren, 2005a), as well as individuals with FASD (Payne et al., 2011a). Clients expect healthcare providers to have expert information, with the ability to clarify discrepancies and to give strong advice; currently, this is not the case for those who seek aid for FASD or alcohol dependency while pregnant (Anderson et al., 2014; McMullan, 2006).

Healthcare providers also play a vital role in prevention and diagnosis (Tough et al., 2005b), and early diagnosis is one of the strongest protective factors against secondary impacts of FASD (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004). As one of the main sources of information where medical professionals report gaining FASD knowledge is medical school (Coons, Clement, & Watson, 2017; Payne et al., 2011b), exploring the knowledge of medical students is of great clinical value. Furthermore, limited research on FASD has been conducted in Ontario, Canada. Therefore, this thesis will investigate the knowledge that future health practitioners gain during their time in medical education in regards to FASD, as well as the advice they would give to women regarding the use of alcohol during pregnancy.

1.1 Literature Review

This literature review underscores the importance of studying the education that future healthcare professionals receive. First, it explores the history behind the diagnosis of FASD, summarizing both sets of currently used Canadian guidelines for diagnosis, as well as the characteristics of the disorder. Next, the confusion that surrounds FASD with respect to healthcare professional opinions and practices is investigated. Third, the effects of the disorder, including both primary and secondary impacts are described. Last, the state of current knowledge and practice of healthcare professionals is considered. Each of these sections inform and provide a rationale for the proposed study.

1.2 History and Diagnosis of FASD

The effects encompassed in FASD, including physical, mental, behavioural and learning disabilities, have lifelong implications (Chudley et al., 2005). The first recognition of these implications is attributed to Lemoine and colleagues (1968) in France. Since then, several different terms have been used to describe these effects, beginning with Fetal Alcohol Syndrome (FAS), the most visible presentation of FASD (Jones & Smith, 1973; Jones, Smith, Ulleland & Streissguth, 1973). FAS is characterized by facial abnormalities, impaired prenatal and/or postnatal growth, and central nervous system (CNS) or neurobehavioural disorders (Chudley et al., 2005). In 1978, it was found that individuals that were prenatally exposed to alcohol experienced cognitive and/or behavioural problems, growth aberration and/or physical deviations at higher frequencies than populations who were not exposed to alcohol; these consequences were termed Fetal Alcohol Effects (FAE; Sampson, Streissguth, & Graham, 1997). Although still popular with educators and non-profit agencies (Fiske & Stockburger, 2005), the term FAE has

since been elaborated on by the United States' Institute of Medicine (IOM), which published recommendations for the diagnosis of FAS in 1996 (Stratton, Howe, & Battaglia, 1996). The diagnostic categories included: FAS with and without a confirmed history of alcohol exposure, partial FAS (pFAS), alcohol related-birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND; Fiske & Stockburger, 2005; Stratton et al., 1996).

The IOM diagnostic criteria for FAS with confirmed alcohol exposure included: (1) confirmed maternal alcohol exposure; (2) evidence of the FAS facial patterns; (3) evidence of growth deficiencies; and (4) evidence of CNS neurodevelopmental abnormalities. A diagnosis of FAS without confirmed alcohol exposure would be given if the individual had the last three criteria. A diagnosis of pFAS was given in if the individual had: (1) confirmed maternal alcohol exposure; (2) the FAS facial phenotype; and either (3a) growth deficiencies; (3b) CNS abnormalities; or (3c) behavioural patterns or cognitive abnormalities that are inconsistent with the individual's development level, which are not explained by familial background or environment (Chudley et al., 2005).

ARBD and ARND, in the IOM criteria, fall under the subheading of alcohol-related effects, or FAE. That said, within the literature, FAE is currently used interchangeably with ARBD and ARND (McAnally, 1995). A diagnosis of ARBD is given when: (1) there is confirmed maternal alcohol exposure; and (2) the individual displays congenital abnormalities, including cardiac, skeletal, renal, ocular, auditory and other malformations and dysplasias. ARND, on the other hand, is assigned when the individual: (1) has confirmed maternal alcohol exposure; and displays either one or both of the CNS abnormalities or behavioural/cognitive abnormalities described in pFAS (Chudley et al., 2005).

The IOM criteria is one of two popular strategies for FASD diagnosis (Chudley et al.,

2005). The second of these is a 4-Digit Diagnostic Code, created by Astley and Clarren (1999), which uses quantitative, objective measurement scales and specific case definitions. The code has since been revised (Astley, 2004), and as of 2005 was used for diagnosis, screening and surveillance throughout the United States and Canada (Chudley et al., 2005). The 4 digits of the code represent the severity of expression of the four key diagnostic features of FAS: (1) growth deficiency; (2) the FAS facial phenotype; (3) CNS damage/dysfunction; and (4) gestational exposure to alcohol. Each feature's magnitude of expression is ranked independently on a 4-point Likert scale, with 1 reflecting total absence of the feature and 4 reflecting extreme expression (Astley, 2004). This 4-Digit Diagnostic Code is also designed to be used by a multidisciplinary team of professionals, normally including a physician, psychologist, occupational therapist, speech-language pathologist and family advocate (Fiske & Stockburger, 2005). Other recommendations for a team include a coordinator for case management (such as a nurse or social worker), a physician specifically trained in FASD diagnosis, a psychologist, an occupational therapist and a speech-language pathologist. With this team, additional professionals such as addiction counsellors, childcare workers, cultural interpreters, mental health workers, parents or caregivers, probation officers, psychiatrists, teachers, vocational counselors, nurses, geneticists or dysmorphologists, neuropsychologists, and/or family therapists are also considered for inclusion. Some clinics choose to use this 4-Digit Diagnostic Code along with the IOM criteria, integrating the two for modern day diagnosis (Chudley et al., 2005). Based on this knowledge, Chudley and colleagues (2005) created the first set of Canadian guidelines for diagnosis for the disorders included under FASD at the time. FASD became the umbrella term to refer to FAS, pFAS, and FAE (including ARBD and ARND), but FASD itself was not intended to be used as a diagnostic term (Chudley et al., 2005).

The criteria for diagnosis of FAS included: (1) evidence of pre/postnatal growth impairment through at least one of the following presentations: birth weight/length at/below the 10th percentile for gestational age, height/weight at/below the 10th percentile for age, and/or a disproportionately low weight-to-height ratio; (2) simultaneous presentation, at any age, of all three of the following facial abnormalities: short palpebral fissures as indicated by being 2 or more standard deviations below the mean, a smooth/flattened philtrum as ranked 4 or 5 on the lip-philtrum guide, and a thin upper lip, also ranked 4 to 5 on the lip-philtrum guide; (3) evidence of impairment in three or more of the following CNS domains: hard and soft neurologic signs, brain structure, cognition, communication, academic achievement, memory, executive functioning, abstract reasoning, attention deficit/hyperactivity, adaptive behaviour, social skills and social communication; and (4) confirmed or unconfirmed maternal alcohol exposure (Chudley et al., 2005).

The criteria for pFAS included: (1) simultaneous expression of two of the above explained facial abnormalities; (2) evidence of impairment in three or more of the previously described CNS domains; and (3) confirmed maternal exposure (Chudley et al., 2005). The criteria for ARND included: (1) evidence of impairment in three or more of the previously described CNS domains; and (2) confirmed maternal alcohol exposure. The criteria for ARBD were less specific, and, as such, this diagnosis was recommended to be used with caution. However, it did include a list of congenital anomalies, including malformations and dysplasias (Chudley et al., 2005).

Since these 2005 guidelines were implemented, research in FASD has expanded and evolved, and the guidelines have been challenged (Cook et al., 2015). As an example, McLennan (2015) claims that the inclusion of partial effects through categories such as pFAS and ARND,

although an attempt to include those who may not show typical FASD manifestations, results in a problematic overlap with those who were exposed to alcohol prenatally, but whose mental health challenges are not due to this exposure. For instance, the diagnostic criteria of ARND of CNS impairment in three or more of the listed domains would be commonly found in children with a variety of mental health disorders, some of whom may not have been prenatally exposed to alcohol (McLennan, 2015).

These concerns with the usage of Chudley and colleagues' (2005) guidelines have led to a revision by Cook et al. (2016), encompassing a set of recommendations on the screening, referral and support for pregnant/postpartum women and for those at risk for FASD. The recommendations extend to the medical assessment (including family history, maternal alcohol history, physical examination and differential diagnosis), the sentinel facial features, the neurodevelopmental assessment, the nomenclature and diagnostic criteria, the diagnostic team and special considerations to be taken in assessing infants and young children. The sentinel facial features (SSFs) refer to the three main facial abnormalities used to diagnose FAS, those being: short palpebral fissures, a smooth philtrum, and a thin vermilion border of the upper lip (Hoyme et al., 2016).

The main changes in the 2016 guidelines include: (1) special considerations when diagnosing infants, young children and adults; (2) a new at-risk category, meant to capture individuals who do not necessarily meet the diagnostic criteria, but are still at-risk for FASD; (3) the removal of "growth" as a criterion; (4) the revision, renaming and redefining of some CNS domains that are evaluated in the neurodevelopmental assessment; and (5) FASD as a diagnosis, as opposed to an umbrella term. With the inclusion of FASD as a diagnostic term, the FAS, pFAS and FAE categories have been removed altogether (Cook et al., 2015).

1.3 Effects of FASD

The primary impact of prenatal alcohol exposure is the direct brain changes that result in cognitive impairment in individuals with FASD (Streissguth et al., 2003). Individuals with these brain changes interact with the environment in such a way that a number of secondary impacts have become associated with individuals with FASD (Clark et al., 2004). There is some contradiction regarding the exact specifications of these impacts, both primary and secondary.

Some studies refer to the primary impact of FASD directly as the IOM criteria for diagnosis (Koren, Nulman, Chudley, & Looke, 2003), while others go into more depth, including aspects such as difficulties with memory, planning, generalizing from one situation to another, understanding the concept of time, registering and integrating sensory cues such as temperature and pain, and patience, to name a few (Rutman & Bibber, 2009). These impairments are measured through general intelligence, reading mastery, spelling, math and level of adaptive functioning. Although IQ is widely used to diagnose intellectual disability, defined as an IQ score of under 70 (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators & Centers for Disease Control and Prevention, 2014), many individuals with FASD have an IQ within the “normal” range; Streissguth and colleagues (2003) found only 16% of the individuals in their study legally qualified as having an intellectual disability. In spite of this, these individuals still have impaired mental functioning; it has been found that their academic abilities, living skills, communication skills and adaptive behaviour are well below their IQ levels (Streissguth et al., 2003). Furthermore, within Canada, Clark and colleagues (2004) found only 34% of their clients with FASD to have an IQ of under 70, which is one of the two requirements required in British Columbia to receive community living support services, the other being adaptive skill deficits in two or more areas. However, 81% of clients required a

moderate to high level of care indicating severe deficits in their adaptive skills. The disparity between IQ and adaptive skills suggests that IQ alone should not be used as a criterion to determine the level of care individuals with FASD should receive (Clark et al., 2004). In addition, although the literature reports a connection between prenatal alcohol exposure and cognitive impairment, this relationship is not always present: rather than alcohol causing cognitive impairment, it is more accurate to say that alcohol *can* cause cognitive impairment (Price & Miskelly, 2015). Therefore, it cannot be assumed that individuals who are prenatally exposed to alcohol will always experience intellectual disability, and, if they do, these disabilities may not manifest in the same way.

Secondary impacts, on the other hand, are not present at birth, and arise due to the interaction of the individual's FASD with the expectations of the environment around them. As such, there are possibilities for interventions to reduce and/or prevent these effects (Clark et al., 2004; Streissguth et al., 2003). Some of these consequences include: mental health problems, disrupted school experiences, trouble with the law, confinement through inpatient treatment or incarcerations, inappropriate sexual behaviour, alcohol/drug problems, dependent living, problems with employment (Koren et al., 2003; Streissguth et al., 2003), and problems with parenting (Clark et al., 2004). Notably, an IQ of under 70 did not significantly change the likelihood of experiencing secondary impacts, while deficiencies in adaptive functioning did, lending further evidence that the primary manifestation of FASD is not a below average IQ (Clark et al., 2004). The current emphasis on IQ has further consequences, as having an IQ of over 70 is a risk factor for adverse life outcomes due to being associated with delayed diagnosis of FASD (Streissguth et al., 2003).

Mental health problems are among the most prevalent of secondary impacts, being

reported in upwards of 90% of FASD samples (Clark et al., 2004; Koren et al., 2003; Streissguth et al., 2003). Streissguth and colleagues (2003) also found ADHD in 60% of children with FASD, and, in the adults, clinical depression to exist in the majority of the sample, along with 23% attempting suicide. Clark and colleagues (2004) reported that 87% of adults with FASD had experienced verbal, physical and/or sexual abuse. This proportion drops to 77% when excluding verbal abuse, a similar proportion to the 72% of individuals with FASD found by Streissguth and colleagues' (2003) who experienced domestic, physical and/or sexual violence.

Dependent living and employment problems are the next most common secondary impact, with a prevalence rate of 80% (Koren et al., 2003; Streissguth et al., 2003). Only 8% of Streissguth and colleagues' (2003) sample reported no problems with independent living or employment. Disrupted school experience varies depending on the age group, but Streissguth and colleagues (2003) found it ranged from 43% of school-aged children to 70% of individuals by adulthood. From age 12 years and up, about 60% of individuals with FASD will have trouble with the law, with the most common offenses being crimes against persons, such as theft, running away, and assault, among others (Streissguth et al., 2003). However, Clark and colleagues (2004) found 92% of adults with FASD were described as vulnerable to manipulation by their caregivers. This finding has implications in regards to the legal system, especially in considering issues such as false confessions, acquiescence, consent and difficulty understanding cautions, which are influenced by vulnerability to manipulation (Beail, 2002; Lindsay, 2002; Linhorst, Bennet, & McCutchen, 2002). As a result, incarceration for crimes is the most common confinement experienced by the FASD population (Streissguth et al., 2003), and youth with FASD are 19 times more likely to be confined in a young offender's facility than their non-affected peers (Popova, 2011). Trouble with law may be connected to other secondary impacts

associated with FASD, such as substance abuse, which exists at a rate of five times that of the general (Streissguth et al., 2003), or to inappropriate sexual behaviour, which was found in 45-50% of those with FASD (Koren et al., 2003; Streissguth et al., 2003).

FASD-related disabilities are influenced by several risk factors, which can impact the severity of the disorder. FASD is unique in that each person who receives the diagnosis has a mother who consumed alcohol to some extent, and this, in itself, has various associations. May and Gossage (2011) describe three types of risk factors: (1) Host, which includes aspects of the mother such as age (25 and over), cigarette smoking, depression/psychological distress, and particular alcohol dehydrogenase polymorphisms; (2) Agent Exposure, which includes the specifics of alcohol exposure to the fetus such as binge drinking (three or more, per occasion), drinking outside of meals, change in nutritional status during pregnancy, and choosing beer as opposed to other alcoholic drinks; and (3) Environment, which is specific to sociocultural factors the mother has experienced, such as low SES, being unmarried but living with a partner, social isolation from mainstream society, and having little or no knowledge of FASD. Risk factors can extend after birth; for example, having an IQ over 70 is associated with higher risk for adverse life outcomes, likely due to the fact that lower IQ is associated with increased likelihood for intervention (Streissguth et al., 2003), and therefore, higher IQ may delay diagnosis. Early diagnosis, on the other hand, along with child-rearing in a positive stable environment has been found to increase the odds of avoiding adverse life outcomes from 2- to 4-fold (Streissguth et al., 2004).

Many of the secondary impacts of FASD are preventable, and with appropriate intervention, may be reduced. Clark and colleagues (2004) specify that factors that protect against secondary abilities, from strongest to weakest, are as follows: (1) living in a

stable/nurturing home for over 72% of life; (2) being diagnosed before the age of 6 years old; (3) never having experienced violence against oneself; (4) staying within each living situation for an average of more than 2.8 years; (5) experiencing a good quality home from age 8 to 12 years old; (6) being eligible and able to apply for supports and community living services; (7) being diagnosed with FAS rather than FAE; and (8) having basic needs met for at least 13% of the individuals' life. Importantly, living with a caregiver (in this case, friends, family or support workers) was found to be significantly associated with not getting into trouble with the law, while a minimal to low level of care was associated with sexually inappropriate behaviour (Clark et al., 2004).

1.4 Confusion Surrounding FASD

Many barriers to appropriate intervention exist in the form of confusion around FASD. Although the new guidelines (Cook et al., 2015) have been created to account for some of the diagnostic confusion, most Canadian clinics are still using the 2005 guidelines (Clarren et al., 2015), although not necessarily in the same way. For example, funding is a common barrier to being able to staff the full recommended multidisciplinary team, meaning that the method, and possibly the quality, of intervention differs between clinics (Clarren, Lutke, & Sherbuck, 2011). In addition, not all individuals are diagnosed at an FASD-specific clinic, and research on diagnosis in areas without FASD-specific programs is limited. As of 2011, in Canada, only British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick and the Yukon reported having FASD specific programs (Clarren et al., 2011).

This difference in experience is only going to grow larger, as with the release of the new guidelines (Cook et al., 2015), there is going to be a period of implementation where both sets of guidelines are being used. This transitional period may lead to further disorganization through

differing diagnoses, especially considering the transition of FASD from an umbrella term to a diagnostic term, and the removal of FAS and FAE from diagnostic categories altogether (Cook et al., 2015).

Further confusion is created by the high rates of co-morbidity of FASD with other disorders. As reported by Streissguth and colleagues (2003), ADHD is commonly found in children, clinical depression is commonly found in adults, and substance abuse exists in the FASD population at a rate that is five times that of the general population. Clark and colleagues (2004) report that there is insufficient evidence as to the nature of the relationship between FASD and other mental health problems, but that there are several possible theories as to why this relationship exists: (1) the genes that result in susceptibility to alcoholism and mental health problems may be the same (Mueser, Drake, & Wallach, 1998); (2) women with mental health problems may use alcohol as a form of self-medication to deal with the symptoms of their disorder, or the side effects of medications (Phillips & Johnson, 2001); (3) the mental health problems, such as ADHD, may be an actual component of FASD and not a separate diagnosis (Coles, 2001; O'Malley & Nanson, 2002); and (4) the lack of understanding and support for those with FASD contributes to the development of further mental health problems (Phillips & Johnson, 2001).

Co-morbidity complicates diagnosis, treatment, and clinical course (Skidmore, Tate, Drapkin, & Brown, 2014). For example, comorbidity can result in the improper diagnosis of individuals with FASD, resulting in inappropriate treatment (Nash et al., 2006), such as an individual comorbid for FASD and ADHD being treated only for ADHD. On the other hand, some reports of comorbidity may be due to the inclusion of partial effects in the old guidelines (Chudley et al., 2005), which broaden the FASD diagnostic criteria to include disorders of which

prenatal exposure to alcohol may not be the primary cause (McLennan, 2015), such as with intellectual disability.

There are also misconceptions in practice, specifically in regards to the FASD continuum. The Public Health Agency of Canada (2005), which conducted a national study across a random sample of Canadian healthcare professionals (including pediatricians, psychiatrists, obstetricians/gynecologists, midwives and family physicians), found that a full 85% of respondents to the questionnaire incorrectly believed that FAE was a less severe form of FAS, and 60% believed that a child diagnosed with FAE had better social outcomes. Less than 60% of professionals correctly identified situations in which a diagnosis of FAE is not used, and there are wide regional variations within Canada regarding the belief that FAE is a partial expression of FAS, ranging from 58% in Québec to 80% in the Prairies. In general, healthcare professionals appear to have acquired more knowledge about FAS than FAE; almost 100% had heard of FAS by 1997, but less than 60% had heard of FAE by the same year (PHAC, 2005).

While 80% and 70% of the participants in the Public Health Agency of Canada (2005) study recognized growth deficiency and facial features, respectively, as distinguishing features of FAS, less than 60% recognized that a combination of growth, facial and brain abnormalities provides the most accurate information to inform diagnosis. Furthermore, although the secondary impacts of emotional disorders, disrupted school experiences, alcohol/drug problems and legal trouble were recognized as being associated with FAS by over 60% of the healthcare professionals, only 35% recognized inappropriate sexual behaviour as a secondary impact of FAS (PHAC, 2005).

Further confusion exists between healthcare providers in regards to whose role it is to manage FASD. Coons and colleagues (2017) found that 88.1% of family physicians and 69.2%

of midwives reported that it was the responsibility of the physician to manage the issue of maternal alcohol use, while 72.5% of family physicians and 56.6% of midwives reported it was the responsibility of the midwives to manage this issue. Interestingly, 5.3% and 9.0% of respondents were unsure as to if the management of FASD was the responsibility of the family physician or midwives, respectively (Coons et al., 2017). This lack of communication and understanding is problematic, as role clarity is crucial to promote successful interprofessional collaboration. The absence of role clarity could lead to challenges in providing interdisciplinary care to pregnant women (Munro, Kornelsen, & Grztbowski, 2013), as well as to individuals with FASD, as one healthcare professional may have assumptions as to the type of care that individuals are getting from other healthcare professionals, and without proper communication between them, certain aspects of care could be neglected. Effective communication is especially important for pregnant women and individuals with FASD, as proper care for these individuals involves a team full of professionals of varying disciplines (Chudley et al., 2005; Cook et al., 2015; Fiske & Stockburger, 2005).

1.5 Knowledge and Practice of Healthcare Professionals Regarding FASD

In some areas, knowledge regarding FASD has improved. For example, the Public Health Agency of Canada (2005) reported that the misconception that FASD was associated with ethnocultural background, specifically in regards to Indigenous peoples (Hanscom, 2008), no longer seems to be present. They also reported that healthcare professionals display increased awareness and agreement on the role of alcohol as a dangerous substance with respect to fetal exposure. However, 25% of those surveyed reported the belief that the effects of alcohol on the

fetus are unclear (PHAC, 2005), and in the United States, 45% of obstetrician-gynecologists reported the same belief (Anderson et al., 2010). Similarly, an Australian study reported that 32% of midwives believed that infrequent consumption of an alcoholic drink by a pregnant mother was not harmful to the fetus or the mother (Payne et al., 2014). These conclusions are in contrast to other literature that concludes that there is no safe level or time for women to consume alcohol during pregnancy (Day et al., 2013). This disagreement may be due, in part, to the fact that the mechanisms through which alcohol causes cognitive deficits are so complex (Goodlett et al., 2005; Pretrelli et al., 2018), therefore making it difficult to identify when prenatal alcohol exposure is the primary cause of a disorder. Misdiagnosis of alcohol exposure as the leading etiology can be problematic (McLennan, 2015; Price & Miskelly, 2015), and there are possible alternate explanations, such as patterns of binge drinking being predictive of brain damage as opposed to simply exposure to alcohol (Price & Miskelly, 2015).

That said, only 40-50% of Canadian healthcare providers reported frequently discussing the risks of alcohol exposure during pregnancy to women of childbearing age (PHAC, 2005; Tough et al., 2005b), although 97% reported routinely collecting information regarding alcohol intake during pregnancy, and 86% reported investigating pre-pregnancy alcohol use (PHAC, 2005). However, even in the event that the discussion was had, the information was not always passed onto the full healthcare team of the individual in question; Anderson and colleagues (2010) reported that less than half of obstetrician-gynecologists always communicated information about alcohol use during pregnancy to the newborn's pediatrician. This finding has problematic implications in regards to the quality of the interdisciplinary care that pregnant women and individuals with FASD are getting.

A reoccurring finding within the FASD literature involves how prepared healthcare

professionals feel to care for their patients. A cross-Canada survey found that only half of the respondents reported feeling prepared to care for mothers dealing with alcohol use/dependency, although 71% reported feeling prepared to access resources for them (PHAC, 2005). In particular, only 6% of pediatricians, who play a key role in the early diagnosis and management of FASD, reported feeling very prepared to deal with FAS. In a separate study, 67% of pediatricians believed that a diagnosis of FASD may lead to the child and/or their family being stigmatized (Payne et al., 2011a), and, in spite of the fact that early diagnosis is one of the strongest protective factors against secondary impacts of FASD (Clark et al., 2004), only 66% believed early diagnosis may improve treatment plans (Payne et al., 2011a).

These findings are not universal; for example, rural areas tend to report unique results with respect to FASD (Tough et al., 2008a; Coons et al., 2017). Rural healthcare providers are more likely to engage in conversation about the risks of alcohol use during pregnancy to women of child bearing age in comparison to urban healthcare providers (Coons et al., 2017). Similarly, and perhaps connected, is the finding that rural healthcare providers were more likely to report feeling prepared in caring for mothers who are using or dependent on alcohol (Coons et al., 2017), a finding supported by previous studies (Tough, Erdiger, Hicks & Clarke, 2008a). These differences between rural and urban providers may be due to increased exposure to the disorder, as the reported prevalence rates of FASD tend to be higher in rural areas when compared to urban areas (Tough et al., 2008a; Coons et al., 2017).

Taken together, the inconsistencies and misconceptions surrounding information on FASD can have problematic implications. Anderson and colleagues (2014) found that when pregnant women were exposed to conflicting information from different sources, they would rely on their healthcare providers, who they viewed as reliable sources with expert knowledge, for

clarification. However, the belief that the effects of alcohol on the fetus are ambiguous (Anderson et al., 2010; Payne et al., 2014; PHAC, 2005) leads to an inconsistent message that may result in very different interpretations by both physicians and the general public: (1) if the effects are unclear, then all alcohol should be avoided to prevent any risk of harm to the fetus; or, (2) if the effects are unclear, then one or two drinks will not harm the fetus, since no strong evidence exists specifically to the contrary (Anderson et al., 2014). The latter interpretation is especially problematic, as it will lead to an increased risk of FASD in the exposed fetus.

Healthcare professionals are sending mixed messages because they are receiving mixed messages. The debate continues not only in the media, but in the medical literature as well (Gavaghan, 2009; Lundsberg, Illuzzi, Balnager, Triche & Bracken, 2015). As of the Canadian national study (PHAC, 2005), healthcare professionals reported getting their knowledge primarily through academic journals, followed by training and seminars, but reported that the highest barrier to diagnosing FAS was lack of training specific to it. In more recent years, there seems to be a move towards getting information from mass media; Coons and colleagues (2017) report that 44% of healthcare professionals reported receiving information from the mass media, while Payne and colleagues (2011b) report that fewer professionals get their knowledge of FASD from scientific journals and books as compared to an earlier study of the same population (2011a). In spite of these findings, the main sources of FASD information seems to come from journals and books (Payne et al., 2011b; Coons et al., 2017) or from medical school, residency or fellowship (Coons et al., 2017).

1.6 Purpose and Rationale

This study investigated the knowledge that Northern Ontario School of Medicine (NOSM) students hold in regards to FASD, as well as developmental disabilities in general. FASD is the leading non-genetic cause of intellectual disability in the western world (PHAC, 2005). However, the mechanisms through which alcohol causes cognitive deficits are complex (Goodlett et al., 2005; Pretrelli et al., 2018), and healthcare professionals may convey mixed messages to their patients (Anderson et al., 2010; Payne et al., 2014; PHAC, 2005). As a result, professionals feel underprepared (Payne et al., 2011a; PHAC, 2005; Tough et al., 2005a), clients feel under supported (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Ryan, Bonnett, & Gass, 2006; Salmon, 2008; Sanders & Buck, 2010; Watson, Hayes, Coons, & Radford-Paz, 2013), and the lack of understanding and support for those with FASD contributes to the development of further mental health problems (Phillips & Johnson, 2001). Healthcare providers also play a vital role in prevention and diagnosis (Tough et al., 2005b), and early diagnosis of FASD is one of the strongest protective factors against the secondary impacts of FASD (Clark et al., 2004). However, confusion exists between healthcare providers in regards to whose role it is to manage FASD (Coons et al., 2017), which may be preventing clients from getting the interdisciplinary care they require, as role clarity is crucial for successful interprofessional collaboration (Munro, Kornelsen, & Grztbowski, 2013).

Among other directions, studies call for the periodic monitoring of the knowledge of healthcare professionals in order to support individuals with FASD (PHAC, 2005), and as one of the main sources of information that medical professionals report gaining FASD knowledge from is medical school (Coons et al., 2017; Payne et al., 2011b), exploring the knowledge of medical students could be of great clinical value. Furthermore, although a significant amount of FASD-

specific research is Canadian, limited research has been specific to the province of Ontario, and even less so to Northern Ontario. Therefore, this study seeks focus on medical students within Northern Ontario by exploring the knowledge of students at NOSM, and the implications their learning experiences will have for standards of care in the future, when these students begin to practice. This study used a two-phase, sequential mixed methods approach.

1.7 Research Question

The main objective of this study was to explore the question:

What knowledge do Northern Ontario School of Medicine (NOSM) students hold in regards to Fetal Alcohol Spectrum Disorder (FASD)?

In this context, knowledge was defined as the information, understanding and/or skill that was acquired from society, medical education or experience. From this question, several sub-questions emerged, such as:

1. Where do developmental disabilities, such as FASD, fall within the NOSM curriculum?
2. How confident do these students feel in the knowledge that they do hold on the topic of FASD, or developmental disabilities in general?
3. How prepared do these students feel to give advice to clients regarding FASD or its surrounding topics?
4. What are the barriers to learning about FASD, or developmental disabilities in general?
5. What sort of resources and/or changes would students like to see to improve their learning about FASD and/or other developmental disabilities?

By exploring the above sub-questions, this study sought to attain a holistic perspective of the learning experience of undergraduate medical students in Northern Ontario in regards to FASD.

1.8 Methodology: Mixed Methods

This cross-sectional study implemented a two-phase, sequential explanatory mixed methods approach (Tashakkori, & Teddlie, 2010). Previous literature has had a quantitative focus, but the use of a mixed methods approach adds meaning to the numbers, thereby allowing for a more in-depth examination of the research question (Johnson & Onwuegbuzie, 2004).

The qualitative component of the methods was informed by basic interpretive inquiry (Merriam, 2009) in the form of semi-structured interviews and scenario-based vignettes, while the quantitative component was measured through the use of the questionnaires described below.

Participants

NOSM students, from both the Laurentian University and Lakehead University sites and in all years of undergraduate education, were recruited as participants. Students were recruited by way of a brief summary of the project (Appendix A), through a recruitment e-mail (Appendix B) sent out to all students, through an edition of the bi-weekly NOSM Learner Affairs Newsletter, and through inclusion of a recruitment message on the NOSM website under Research (until June 20th, 2018). All participants who completed Phase I were invited to complete Phase II; those who completed Phase II were given a \$5 Amazon gift card as an incentive.

Procedure

Phase I consisted of the administration of two online questionnaires regarding knowledge of FASD, as well as other developmental disabilities. Phase II, conducted with students who

completed Phase I, consisted of semi-structured interviews, and included questions pertaining to a scenario-based vignette.

Phase I:

The first phase consisted of two questionnaires, taking approximately 20 to 30 minutes to complete. Each questionnaire was completed through REDcap (Research Electronic Data Capture), a secure, online application used to capture data for research studies (Harris et al., 2009). Although the reliability and validity of these questionnaires have not been assessed, they have been used in previous studies (e.g. Coons et al., 2017).

Adapted Healthcare Student Questionnaire (Appendix C): Students filled out an adapted version of the Healthcare Student Questionnaire (Isaacs, Minnes, Burbidge, Loh, & Versnel, 2012; Minnes, Isaacs, Burbidge, Loh, & Versnel, 2012), previously adapted from the McGill Inclusive Education Questionnaire (Daniel & Cornish, 2006; Daniel, 2011). This questionnaire consists of more general questions regarding demographic information, experiences with the subject, knowledge of developmental disabilities, areas of improvement in regards to knowledge, among other topics. This questionnaire provided the base knowledge and context of each participant.

The Fetal Alcohol Spectrum Disorder Survey for Healthcare Students (Appendix D): In the same REDcap survey, students completed the Fetal Alcohol Spectrum Disorder Survey for Healthcare Students, which was adapted from the Fetal Alcohol Syndrome Survey for Health Professionals (Clarke, Tough, Hicks, & Clarren, 2005; Tough et al., 2005b; Tough, Clarke, Hicks & Cook, 2006; Tough, Clarke & Cook, 2007; Tough et al., 2008a; Tough, Hicks, Davey & Clarke, 2008b). This survey assesses FASD more specifically, and includes questions regarding perceived competency, prevention, diagnostic issues, among other topics. The survey also

includes short answer questions regarding various definitions, for example, to capture student perceptions of a “moderate level of alcohol consumption”.

Phase II:

As part of the survey, students were invited to leave their contact information if interested in participation in Phase II of the study. This phase was focused on qualitatively understanding the NOSM students’ knowledge of FASD, as well as their perceived competency in working with individuals with FASD and their families. This phase consisted of interviews and vignettes, with the whole process taking approximately 30 minutes to one hour to complete.

Semi-Structured Interviews (Appendix E): Those who agreed to participate in Phase II completed a semi-structured interview, which took place online through the use of video chat services such as Zoom and BlueJeans. Questions involved students’ current knowledge of FASD and alcohol, sources of this knowledge, confidence and comfort in their knowledge and advice on FASD and/or other developmental disabilities, previous experience with these individuals, advice regarding alcohol use to pregnant individuals, and other topics. These interviews also included a scenario-based narrative vignettes.

Scenario-Based Narrative Vignettes (Appendix F): As part of the semi-structured interview, students were presented with one of four vignettes, all of which are related to FASD in some way. After reading the vignette, students were asked about their first impressions, the advice they would give to the individual described, their attitudes towards any risks that were taken by the individual, and the comfort they would feel in addressing the situation.

Data Collection and Analysis

Participants ranged in age from 23 to 36 years, with a mode of 24 years. A total of 24 individuals participated in Phase I; however, only 18 continued the surveys to completion. The

majority of participants were female ($N=18$), and from NOSM's Sudbury location ($N=21$).

Three participants had been pregnant before, 17 were single, five were married, and three were living with a partner upon survey completion. Participants were students from all four years of NOSM undergraduate education: four individuals were completing their first year, three completing their second, 12 completing their third, and five completing their fourth.

Once collected, survey data were imported into SPSS (Statistical Package for the Social Sciences) for exploratory analysis (Mayers, 2013). Descriptive statistics for all measures were computed, such as means and standard deviations for continuous measures, and frequencies for discrete data. All available data were included in the analysis; that is, incomplete surveys were still used for the questions that were completed; otherwise, these participants were excluded for the questions they missed. For relevant questions, participants were also stratified by year of education.

Participants in Phase II included two first-year students (Olivia and Morgan), four third-year students (Felicia, Joshua, Sophie and Cynthia), and two fourth-year students (Anna and Maria). As such, eight individuals in total completed the interviews, with participants being mostly female ($N=7$).

Qualitative data were assessed using thematic analysis, as detailed by Braun and Clarke (2006). All interviews were transcribed, while noting initial ideas. Pseudonyms were used for all participants, as well as other students they may have mentioned. Once familiarized with the data, initial codes for potential themes and patterns were generated. The codes were then collated into themes, which were reviewed with respect to each other, the entire data set, and the initial research question. Once the themes were finalized, they were named, clearly described, and integrated to convey the story of the data within the write-up of the articles below. These themes

allowed for description, explanation and further exploration of the information provided by the questionnaires completed in Phase I.

Ethical Considerations

An ethics application was approved by the Laurentian University Research Ethics Board, Ontario, Canada, which was in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants (REB#6009963; Appendix G). Consent forms were included in both Phase I (Appendix H), and Phase II (Appendix I) prior to participation. Within Phase I, every effort was made to ensure the anonymity of participants; student responses to the questionnaires were separated from any identifying demographic or personal information, through the use of a separate page for each component within REDcap. In Phase II, interviews were completed through video chat services such as Zoom and BlueJeans. Throughout the study, participants were free to withdraw at any point with no penalty. All data files were password protected, and pseudonyms were used in all transcriptions. Only the audio from the digital recording of the interviews were used for transcription. In addition, community resources were available for all participants if necessary (Appendix J).

1.9 Overview of Articles

The results of this thesis will be presented via two articles. The first article, within Chapter 2, focuses on the knowledge students hold in regards to FASD. In doing so, their knowledge about alcohol use is also discussed, as well as their perceived competency in giving advice regarding these topics. This paper is to be submitted to Fetal Alcohol Research in the Journal of Population Therapeutics and Clinical Pharmacology.

The second article, within Chapter 3, delves into the learning experiences of these students. As students rarely had experience with FASD specifically, this paper discusses their experiences in learning about developmental disabilities in general: how their learning took place, what they perceive as the barriers to this learning, and any solutions or ideas for change that they may have. This paper is to be submitted to the Journal on Developmental Disabilities.

Chapter 2: Article on NOSM Student Knowledge and Competency

“I really feel like I don’t know much about it”: Knowledge and perceived competency of Northern Ontario School of Medicine Students on Fetal Alcohol Spectrum Disorder

Celisse Bibr, Dr. Shelley Watson, Dr. Kelly Harding, Dr. Sylvie Larocque, Dr. Diana Urajnik

Laurentian University

Article to be submitted to Fetal Alcohol Research
in the Journal of Population Therapeutics and Clinical Pharmacology

“I really feel like I don’t know much about it”: Knowledge and perceived competency of Northern Ontario School of Medicine Students on Fetal Alcohol Spectrum Disorder

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term describing the range of effects of prenatal exposure to alcohol.^{1,2} FASD is the leading non-genetic cause of intellectual disability in the Western world,^{1,3} with a prevalence estimated at 24 to 48 per 1000 children.⁴ Individuals with FASD face a number of secondary adverse outcomes, such as contact with the criminal justice system or disruptions in schooling.^{2,3} These secondary outcomes can be minimized by early diagnosis; however, diagnosis of FASD by healthcare providers is often delayed or not considered due to its complex nature.^{3,5} The mechanisms through which alcohol causes cognitive deficits are diverse,⁶ and a significant portion of healthcare professionals believe the effects of alcohol on the fetus to be unclear.^{3,7,8} The belief that the effects of alcohol on the fetus are ambiguous^{3,7,8} can lead to two interpretations by physicians and the general public: (1) if the effects are unclear, then all alcohol should be avoided to prevent any risk of harm to the fetus or; (2) if the effects are unclear, then one or two drinks will not harm the fetus, because no strong evidence exists specifically to the contrary.⁷ The latter interpretation is especially problematic, as it could lead to an increased risk of FASD in the exposed fetus.

Limited findings regarding Canadian physicians demonstrates a lack of knowledge in several critical areas including: the diagnostic criteria of FASD; long term outcomes of prenatal exposure to alcohol; FASD identification; and screening tools for alcohol dependency.³ Providers also report feeling unprepared to care for pregnant clients showing signs of alcohol dependency,^{3,9} as well as individuals with FASD.¹⁰ Healthcare providers play a vital role in prevention and diagnosis,¹¹ and early diagnosis is one of the strongest protective factors against

secondary adverse outcomes associated with FASD.¹² Canada is currently in a period of transition to a new set of FASD guidelines for diagnosis, which has included major changes in labelling and diagnostic criteria.¹ How and/or if these guidelines have been disseminated throughout medical education is unknown.

Patients receive an overwhelming amount of information regarding their pregnancies, and rely on their healthcare providers to hold expert information and to be able to clarify any discrepancies between other sources of information.^{13,14} Currently, however, this is not the care for those who seek aid for FASD or alcohol dependency while pregnant; the advice given to the same individuals by different healthcare professionals is often inconsistent, and only adds to the confusion.^{13,14} As one of the main sources of information where medical professionals report gaining FASD knowledge is medical school,^{15,16} exploring the knowledge of students during their time in formal education is of great clinical value; this knowledge will be brought with them into their future practices, and it will therefore directly impact the level of care that individuals with FASD and their families are getting. Targeting this population early in their professional careers will allow for the identification of their level of knowledge, and provide a basis upon which to build future educational initiatives. In addition the reported prevalence rates of FASD tend to be higher in rural areas when compared to urban areas,¹⁵ and limited research has been conducted in Northern Ontario. Therefore, this study uses a mixed methods approach to investigate the knowledge that future healthcare practitioners gain during their time in medical education in regards to FASD and surrounding topics, such as the use of alcohol during pregnancy, as well as the perceived level of competence of these students.

Methods

This cross-sectional study implemented a two-phase, sequential explanatory mixed methods approach.¹⁶ An ethics application was approved by the Laurentian University Research Ethics Board, Ontario, Canada, which is in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants (REB#6009963). Undergraduate medical students from all years of schooling (not including residents) and from both sites (i.e., Lakehead and Laurentian University) of the Northern Ontario School of Medicine (NOSM) were invited to participate in this study.

Phase I was completed through the use of two questionnaires: the Healthcare Student Questionnaire and the Fetal Alcohol Spectrum Disorder Survey for Healthcare Students. The first questionnaire, previously adapted from the Healthcare Student Questionnaire,^{17,18} provided the context and base knowledge of each participant regarding developmental disabilities. The second questionnaire was adapted from the Fetal Alcohol Syndrome Survey for Health Professionals,^{11,19-24} which assesses knowledge regarding FASD more specifically, including topics such as prevention, diagnostic issues, and various definitions, such as what the student perceives as a “moderate level of alcohol consumption”. Although the validity and reliability of these questionnaires has not been assessed, they have been successfully used in previous studies, such as Coons, Clement, & Watson (2017).¹⁵

All participants who completed the questionnaires were invited to participate in Phase II, with the incentive of a \$5 (CAD) Amazon gift card. This phase was informed by basic interpretive inquiry²⁵ in the form of 30- to 60-minute semi-structured interviews that included responses to scenario-based vignettes, as adapted from previous studies.^{26,27} These interviews took place over video chat services, such as Zoom and BlueJeans, in order to accommodate for

student schedules and locations. There were four vignettes that were cycled, with each participant reading and responding to one of the four during their interview.

Once collected, survey data were imported into SPSS (Statistical Package for the Social Sciences) for exploratory analysis.²⁸ Analysis was conducted largely through the use of descriptive statistics. Partially completed surveys were still used in analysis for the questions that were answered; otherwise, these participants were excluded in the analysis for the questions that were missed. For relevant questions, participants were also stratified by year of education. Qualitative data were assessed using thematic analysis, as detailed by Braun and Clarke,²⁹ which allowed for description, explanation, and further exploration of the information provided by the questionnaires completed in Phase I. As such, the themes that emerged from Phase II were used to build upon the results of Phase I in order to gain a more accurate insight into the student perspective, as well as increase the validity of this study's results through methodological triangulation.

Results

Phase I participant characteristics are provided in Table 1, and Phase II participant characteristics are described in Table 2. A total of 24 participants responded to the questionnaires (with 18 completing them fully), and 8 medical students participated in the interviews. During both phases, information emerged regarding students' levels of knowledge on FASD and alcohol use during pregnancy, as well as their perceived levels of competency in addressing these topics.

Student Knowledge on FASD: Participants had a general understanding of what FASD was: that it was associated with prenatal alcohol consumption, that facial features were involved, and that it was relatively common (see Table 3). However, specifics such as which facial characteristics, which adverse outcomes, and the amount and timing of alcohol consumption

associated with FASD were not as well understood (see Tables 3 and 4). For example, 22.2% of participants marked “I don’t know” when asked if Central Nervous System dysfunction was a characteristic of FASD (Table 3), and 27.8% of participants agreed with the statement “Alcohol’s effect on the fetus is unclear” (Table 4). During the interviews, participants elaborated on, and readily admitted to, gaps in their knowledge. For example, Felicia, a third-year student, said:

I couldn’t really tell you exactly besides [...] there being [...] specific physical manifestations [FASD] can have and neurocognitive manifestations it can have. I can’t really tell you exactly what they are.

Although, overall, students reported having more knowledge on the diagnosis of FASD than the treatment of FASD, the vast majority of respondents reported not being aware of any guidelines for FASD diagnosis (see Table 3). In Phase II, both Morgan and Olivia used the term “Fetal Alcohol Syndrome”, a former diagnostic term under the umbrella of FASD,⁵ without prompting. When asked to elaborate, Morgan explained that she “would use [Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder] interchangeably”. However, some participants in Phase II were somewhat aware of the new Canadian guidelines for diagnosis.¹ Anna stated that she knew “the name [had] sort of changed over time”, and Sophie described Surrey Place Centre’s health watch table as “an excellent resource”, which does reference the new guidelines.³⁰ On the other hand, Morgan, Joshua, and Olivia admitted to not knowing any guidelines for FASD diagnosis.

Student Knowledge on Alcohol Consumption During Pregnancy: The amount and timing of alcohol consumption associated with FASD was another area of confusion. While the majority of participants in both phases agreed that the best advice to give regarding alcohol use

during pregnancy is that “no alcohol is recommended” (see Table 4), there was debate regarding both the level and the timing of alcohol consumption that could conceivably not result in harm to the fetus. In Phase I, 27.8% of participants agreed with the statement “alcohol’s effect on the fetus is unclear”, although the majority disagreed (see Table 4). In Phase II, participants elaborated on some of the confusion surrounding the timing of alcohol consumption. For example, Sophie believed that severity of FASD varied with gestational age, while Olivia believed that there was a greater chance of effect if using alcohol earlier in pregnancy. Joshua elaborated:

The standard line is that there is no known safe limit of alcohol during pregnancy. My interpretation of that and understanding of that is that we know that there are levels that are known to be unsafe. [...] So, it’s not a number we know. And, therefore, our best recommendation is: avoid it completely, and then it’s not going to be a problem.

However, a number of participants indicated that it was common to see a situation where a pregnant woman used alcohol before she knew she was pregnant, and in these scenarios, the lack of knowledge regarding determining “the line in the sand” (Joshua, third-year student) hurt their ability to advise them. As Cynthia explained, students “can’t provide false reassurance”, meaning that they both cannot tell patients that their child definitely will have FASD, but they also cannot say that their child definitely will not. As a result, Anna elaborated “it’s frustrating for both the healthcare professional and for the patient because you’re stuck between a rock and a hard place”. Some students were unsure as to whether FASD was even appropriate to bring up at this point; as Felicia stated:

I don’t know if it really would’ve been appropriate to talk about FASD at that point, when they’re just finding out [the] unexpected news, but [...] I don’t know what I would

say [or] what the right thing would be to say.

Perceived Level of Competence: Felicia’s struggle in finding the “right thing to say” was not an uncommon one; the result of conflicting and unclear knowledge, for these students, was an overall feeling of hesitation regarding how to care for patients in the areas of FASD and alcohol consumption during pregnancy. In Phase I, over half (55%) of respondents reported feeling mildly competent (defined as “could meet some needs”) in meeting the needs of individuals with developmental disabilities, followed by moderately competent (30%; defined as “could meet most needs”). No individual marked very competent (defined as “could meet all needs”), and no fourth-year student marked feeling not very competent (defined as “could meet few needs”), indicating that perceived competency may increase with years of education (see Table 5). However, a majority of students still reported feeling unprepared to care for individuals with FASD, pregnant women, birth mothers, foster parents, and adoptive parents in the area of alcohol dependency, with students feeling the least ready to care for individuals with FASD. In Phase II, students mentioned deferring to their preceptor in scenarios advising pregnant women using alcohol, or needing to do more research before they felt confident in their advice. Cynthia elaborated:

I would feel certainly less comfortable addressing this situation than I would feel comfortable about addressing cigarette smoking during pregnancy [...] I have lots of questions still about how to address [alcohol use during pregnancy].

Similarly, over half of Phase I respondents reported that they did not feel they had enough access to information or resources (at school or online) to meet the needs of individuals with developmental disabilities (see Table 5), and while a majority of students reported feeling prepared to access resources for pregnant women and birth mothers in the area of alcohol

dependency, the majority did not feel ready to access resources for foster parents, adoptive parents, and individuals with FASD in the same area. The results from Phase II elaborated on these differences between topics, indicating that students seemed more comfortable with advising patients around alcohol use during pregnancy, as opposed to diagnosing, treating, or informing patients specifically on the topic of FASD. Morgan, a first-year student, explained:

I think I would be comfortable to say “you shouldn’t be drinking.” I think that part of the conversation I would be okay with, but I think discussing [FASD], potentially...I’m not sure. I don’t think, right now, I would feel comfortable with that.

Discussion

Alcohol use during pregnancy has been the subject of much debate, both in the public media and the academic literature.³¹ Studies report that there is no single mechanism of how alcohol causes cognitive deficits,⁶ that there is no safe level of alcohol consumption during pregnancy,³² and that low levels of consumption not only do not contribute to impairment, but may have positive outcomes³³—all of this information is reported to healthcare professionals in order to be passed onto their patients. But with the confusion in the literature comes a confusing message and, as a result, 28% of medical students in this study reported feeling that the effects of alcohol on the fetus were unclear, a finding that is duplicated in the literature.^{1,7} That said, the majority of students in this study agreed that the best description of the advice to give to pregnant women regarding alcohol use during pregnancy was “no alcohol is recommended”. In Phase II of the study, Joshua elaborated that “the standard line” is “there is no known safe limit of alcohol during pregnancy”, and Anna identified this as a common area of misinterpretation, as it can be understood as there is no known unsafe limit of alcohol during pregnancy, instead. This misinterpretation can ultimately result in pregnant individuals making the choice to drink alcohol

during pregnancy, especially when mixed with the confusing messages they are getting from the media, and, in some cases, from their healthcare professionals.

Although students had a general understanding of FASD, they struggled with the specifics of the disorder, and readily admitted to gaps in their knowledge. As a result, the future physicians of this study reported feeling unprepared to care for, and access resources for individuals with FASD, pregnant women, birth mothers, foster parents, and adoptive parents in the area of alcohol dependency. Although this finding may be expected, due to the students being at an early point in their medical education, this finding is echoed in the literature with currently practicing physicians.³ Therefore, this issue could be addressed not only through Continuing Medical Education strategies to aid physicians currently in practice, but also through Canadian medical education in order to provide a solution in the long-term. Within this study, the students' lack of knowledge produced a lack of confidence in advising clients in these particular situations, and may ultimately mean diminished care for individuals with FASD and their families. Students are under-equipped to address the needs for these individuals; this finding is also replicated in currently practicing physicians.³ In addition, as there is no consensus on a safe level of alcohol use during pregnancy,^{7,31,32} let alone on what effects specific levels will have on the unborn child, students felt that they did not have the knowledge to properly advise a client in a situation where they had drunk alcohol before they knew they were pregnant. As a result, students felt uncomfortable, under-prepared, and “stuck between a rock and a hard place” (Anna, fourth-year student).

The results of this study echo the literature regarding the knowledge and competency of currently practicing healthcare professionals.³ Therefore, it is no surprise that individuals with FASD and their families report feeling under-supported by the medical system³⁴⁻³⁸.

Unfortunately, this lack of understanding and support for those with FASD may contribute to the development of further mental health problems.³⁹ Therefore, this study aimed to explore the knowledge of future healthcare professionals in order to inform curricula and continuing education opportunities, and ultimately work towards improving care for individuals with FASD and their families.

This study is limited by the restrictions of: (1) only collecting data from one medical school; (2) participants being largely female (see Table 1); (3) a small sample size, and; (4) the possibility of students being primed to view alcohol use in a negative light, as they knew of the focus of this study on FASD. In addition, the fact that recruitment was conducted on a volunteer basis means that participants were more likely to have an existing interest in FASD, and therefore may have more knowledge and/or comfort with the topic than students who did not choose to participate. This has implications in regards to non-respondents; this study's results may be an overestimate of the average undergraduate medical student's knowledge and competency surrounding FASD. That said, this study is an important first step in attempting to address the current issues surrounding the care of individuals with FASD and their families.

Ideally, students would like more knowledge (through experience and formal training) on FASD specifically in order to feel better prepared to care for these individuals. Although students have a general concept of what FASD entails, further focus on the details of the disorder should be made readily available to them through curricular opportunities. Students should be provided with clear, concise resources both for their own education, as well as for the education of their patients, including the new Canadian guidelines for diagnosis.¹ In addition, students should be provided with training surrounding how to advise patients in the area of alcohol dependency, especially in how to approach the topic of FASD and provide resources for an

individual who drank alcohol without knowing they were pregnant. It is essential that medical students feel knowledgeable, comfortable, and ready to care for individuals in this area; therefore, future research should explore how to develop, evaluate and implement FASD-specific training programs to prepare these students for their future practices.

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Tables

Table 1: Phase I Participant Characteristics

Characteristic	Results
Gender (N=24)	<ul style="list-style-type: none"> ● Female: N=18 (75.0%) ● Male: N=6 (25.0%)
Campus (N=24)	<ul style="list-style-type: none"> ● Lakehead (Thunder Bay): N=3 (12.5%) ● Laurentian (Sudbury): N=21 (87.5%)
Age (N=24)	<ul style="list-style-type: none"> ● Range: 23-36 ● Mode: 24 (8 participants)
Year of Education (N=24)	<ul style="list-style-type: none"> ● 1st Year: N=4 ● 2nd Year: N=3 ● 3rd Year: N=12 ● 4th Year: N=5
Relationship & Child Status (N=24)	<ul style="list-style-type: none"> ● Single: N=17 (70.8%) ● Married: N=5 (20.8%) ● Living with partner: N=3 (12.5%) ● Currently or previously pregnant: N=3 (12.5%)
Alcohol Use (N=18)	<ul style="list-style-type: none"> ● Drinks per week: <ul style="list-style-type: none"> ○ None: 38.9% ○ 1-2 drinks: 27.8%

	<ul style="list-style-type: none">○ 3-5 drinks: 22.2%○ 5+ drinks: 11.1%● Drinks per occasion:<ul style="list-style-type: none">○ None: 16.7%○ 1-2 drinks: 55.6%○ 3-5 drinks: 22.2%○ 5+ drinks: 5.6%
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Phase I participant characteristics. Students were mostly female and tended to be in the latter two years of medical education.

Table 2: Phase II Participant Characteristics

Year of Education	Students
First-Year Students (<i>N</i> =2)	<ul style="list-style-type: none"> ● Olivia (Female) ● Morgan (Female)
Third-Year Students (<i>N</i> =4)	<ul style="list-style-type: none"> ● Felicia (Female) ● Joshua (Male) ● Sophie (Female) ● Cynthia (Female)
Fourth-Year Students (<i>N</i> =2)	<ul style="list-style-type: none"> ● Anna (Female) ● Maria (Female)

Table 2 notes: Phase II participant characteristics. All students were from the Sudbury (Laurentian) Campus of NOSM, and all but one participants identified as female.

Table 3: Level of Knowledge (FASD)

Topic	Results
Knowledge of Diagnosis of FASD (N=23)	<ul style="list-style-type: none"> ● Extensive: 8.7% ● Moderate: 43.5% ● Limited: 39.1% ● Very Limited: 8.7% ● None: 0%
Knowledge of Treatment of FASD (N=23)	<ul style="list-style-type: none"> ● Extensive: 0% ● Moderate: 30.4% ● Limited: 43.5% ● Very Limited: 26.1% ● None: 0%
Characteristics of FASD: (N=18)	<ul style="list-style-type: none"> ● Prominent forehead: <ul style="list-style-type: none"> ○ Yes: 50.0% ○ No: 11.1% ○ Don't know: 38.9% ● Flat philtrum: <ul style="list-style-type: none"> ○ Yes: 61.1% ○ No: 11.1% ○ Don't know: 27.8% ● Thin upper lip:

	<ul style="list-style-type: none">○ Yes: 83.3%○ No: 5.6%○ Don't know: 11.1%● Short palpebral fissures:<ul style="list-style-type: none">○ Yes: 50.5%○ No: 22.2%○ Don't know: 27.8%● Central Nervous System dysfunction:<ul style="list-style-type: none">○ Yes: 72.2%○ No: 5.6%○ Don't know: 22.2%● Prenatal growth deficiency:<ul style="list-style-type: none">○ Yes: 83.3%○ No: 0%○ Don't know: 16.7%● Postnatal growth deficiency:<ul style="list-style-type: none">○ Yes: 61.1%○ No: 5.6%○ Don't know: 33.3%● Long term emotional disorders:<ul style="list-style-type: none">○ Associated with FASD: 83.3%○ Directly caused by FASD: 11.1%○ Neither: 0%
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- Don't know: 5.6%
- Disrupted school experience:
 - Associated with FASD: 88.9%
 - Directly caused by FASD: 11.1%
 - Neither: 0%
 - Don't know: 0%
- Addictions:
 - Associated with FASD: 83.3%
 - Directly caused by FASD: 0%
 - Neither: 0%
 - Don't know: 16.7%
- Legal problems:
 - Associated with FASD: 83.3%
 - Directly caused by FASD: 0%
 - Neither: 0%
 - Don't know: 16.7%
- Attention deficit disorder:
 - Associated with FASD: 50.0%
 - Directly caused by FASD: 33.3%
 - Neither: 5.6%
 - Don't know: 5.6%
 - Abstained: 5.6%
- Low IQ:

	<ul style="list-style-type: none">○ Associated with FASD: 50.0%○ Directly caused by FASD: 27.8%○ Neither: 11.1%○ Don't know: 11.1%● Inappropriate sexual behaviour:<ul style="list-style-type: none">○ Associated with FASD: 55.6%○ Directly caused by FASD: 0%○ Neither: 11.1%○ Don't know: 33.3%● Hypersensitivity to stimuli:<ul style="list-style-type: none">○ Associated with FASD: 61.1%○ Directly caused by FASD: 11.1%○ Neither: 0%○ Don't know: 22.2%○ Abstained: 5.6%● Behaviour problems:<ul style="list-style-type: none">○ Associated with FASD: 66.7%○ Directly caused by FASD: 33.3%○ Neither: 0%○ Don't know: 0%● Learning disabilities:<ul style="list-style-type: none">○ Associated with FASD: 72.2%○ Directly caused by FASD: 27.8%
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	<ul style="list-style-type: none"><ul style="list-style-type: none">○ Neither: 0%○ Don't know: 0%● Mental health problems:<ul style="list-style-type: none">○ Associated with FASD: 77.8%○ Directly caused by FASD: 0%○ Neither: 0%○ Don't know: 22.2%● Aggressive behaviour:<ul style="list-style-type: none">○ Associated with FASD: 83.3%○ Directly caused by FASD: 0%○ Neither: 0%○ Don't know: 16.7%● Employment difficulties:<ul style="list-style-type: none">○ Associated with FASD: 94.4%○ Directly caused by FASD: 0%○ Neither: 0%○ Don't know: 5.6%● Dependent living arrangements:<ul style="list-style-type: none">○ Associated with FASD: 66.7%○ Directly caused by FASD: 5.6%○ Neither: 5.6%○ Don't know: 22.2%
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<p>Agree/Disagree Statement (<i>N</i>=18)</p>	<ul style="list-style-type: none"> ● “Making a diagnosis of FASD does not change anything for the child” <ul style="list-style-type: none"> ○ Strongly agree: 0% ○ Agree: 0% ○ Disagree: 38.9% ○ Strongly Disagree: 55.6% ○ Undecided: 5.6%
<p>Knowledge of Any FASD Guidelines for Diagnosis (<i>N</i>=18)</p>	<ul style="list-style-type: none"> ● Aware of guidelines: 16.7% ● Unaware of any guidelines: 83.3%
<p>Received Training on FASD (<i>N</i>=23)</p>	<ul style="list-style-type: none"> ● Through a postgraduate program: 39.1% ● Through an undergraduate program: 13.0% ● Other: 8.7% <ul style="list-style-type: none"> ○ Included conferences and community integrated learning sessions ● None: 43.5%

Questionnaire data regarding participant knowledge on FASD.

Table 4: Level of Knowledge (Alcohol Use during Pregnancy)

Topic	Results
Agree/ Disagree Statements (N=18)	<ul style="list-style-type: none"> ● “Alcohol’s effect on the fetus is unclear” <ul style="list-style-type: none"> ○ Strongly agree: 5.6% ○ Agree: 22.2% ○ Disagree: 38.9% ○ Strongly Disagree: 33.3% ○ Undecided: 0% ● “Prenatal exposure is a significant risk factor for brain damage” <ul style="list-style-type: none"> ○ Strongly agree: 50.0% ○ Agree: 33.3% ○ Disagree: 5.6% ○ Strongly Disagree: 0% ○ Undecided: 11.1%
Best Advice Regarding Alcohol Use During Pregnancy (N=18)	<ul style="list-style-type: none"> ● “No alcohol is recommended”: 88.9% ● “Alcohol is only dangerous during the first trimester”: 0% ● “A glass of beer or wine in moderation is OK: 0% ● No specific recommendations would be given: 0% ● Other: 11.1% <ul style="list-style-type: none"> ○ “That there is no safe drinking limit, but that a recent study showed that aside for 'small for gestational age' women who drink a low amount during pregnancy (< ~32g alcohol/week)

	<p>had no adverse effects. So it's best to drink none, but don't beat yourself up if you have had a beer or glass of wine”</p> <ul style="list-style-type: none">○ “There is no safe limit of alcohol during pregnancy therefore we strongly suggest/recommend no alcohol throughout the pregnancy”
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Questionnaire data regarding participant knowledge on the use of alcohol during pregnancy.

Table 5: Perceived Level of Competence

Topic	Results
<p>Perceived Access to Information/Resources for Individuals with Developmental Disabilities (<i>N=20</i>)</p>	<ul style="list-style-type: none"> ● Yes (I do feel I have enough access): 45% ● No (I do not feel I have enough access): 55%
<p>Perceived Competency in Meeting the Needs of Individuals with Developmental Disabilities (<i>N=20</i>)</p>	<ul style="list-style-type: none"> ● Not very competent: 15.0% <ul style="list-style-type: none"> ○ First-years: N=1 ○ Second-years: N=0 ○ Third-years: N=2 ○ Fourth-years: N=0 ● Mildly competent: 55.0% <ul style="list-style-type: none"> ○ First-years: N=2 ○ Second-years: N=1 ○ Third-years: N=5 ○ Fourth-years: N=3 ● Moderately competent: 30.0% <ul style="list-style-type: none"> ○ First-years: N=0 ○ Second-years: N=0 ○ Third-years: N=5 ○ Fourth-years: N=1

<p>Perceived Preparedness to Care for Individuals in the Area of Alcohol Dependency (<i>N</i>=18)</p>	<ul style="list-style-type: none">● Pregnant women:<ul style="list-style-type: none">○ Very prepared: 11.1%○ Prepared: 27.8%○ Unprepared: 33.3%○ Very unprepared: 22.2%○ I will not care for them: 5.6%● Birth mothers:<ul style="list-style-type: none">○ Very prepared: 11.1%○ Prepared: 22.2%○ Unprepared: 38.9%○ Very unprepared: 27.8%○ I will not care for them: 5.6● Foster parents:<ul style="list-style-type: none">○ Very prepared: 5.6%○ Prepared: 22.2%○ Unprepared: 38.9%○ Very unprepared: 27.8%○ I will not care for them: 5.6%● Adoptive parents:<ul style="list-style-type: none">○ Very prepared: 5.6%○ Prepared: 22.2%○ Unprepared: 38.9%○ Very unprepared: 27.8%
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	<ul style="list-style-type: none"> ○ I will not care for them: 5.6% ● Individuals with FASD: <ul style="list-style-type: none"> ○ Very prepared: 5.6% ○ Prepared: 16.7% ○ Unprepared: 50.0% ○ Very unprepared: 22.2% ○ I will not care for them: 5.6%
<p>Perceived Preparedness to Find Resources for Individuals in the Area of Alcohol Dependency (<i>N</i>=18)</p>	<ul style="list-style-type: none"> ● Pregnant women: <ul style="list-style-type: none"> ○ Very prepared: 11.1% ○ Prepared: 55.6% ○ Unprepared: 27.8% ○ Very unprepared: 0% ○ I will not care for them: 5.6% ● Birth mothers: <ul style="list-style-type: none"> ○ Very prepared: 11.1% ○ Prepared: 55.6% ○ Unprepared: 27.8% ○ Very unprepared: 0% ○ I will not care for them: 5.6% ● Foster parents: <ul style="list-style-type: none"> ○ Very prepared: 11.1% ○ Prepared: 16.7%

	<ul style="list-style-type: none"> ○ Unprepared: 66.7% ○ Very unprepared: 0% ○ I will not care for them: 5.6% ● Adoptive parents: <ul style="list-style-type: none"> ○ Very prepared: 11.1% ○ Prepared: 22.2% ○ Unprepared: 61.1% ○ Very unprepared: 0% ○ I will not care for them: 5.6% ● Individuals with FASD: <ul style="list-style-type: none"> ○ Very prepared: 11.1% ○ Prepared: 27.8% ○ Unprepared: 55.6% ○ Very unprepared: 0% ○ I will not care for them: 5.6%
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Questionnaire data regarding the perceived level of competency of respondents. Definitions included: not very competent (could meet few needs), mildly competent (could meet some needs), moderately competent (could meet most needs), and very competent (could meet all needs expertly).

Chapter 3: Article on Medical Student Barriers to Learning and Ideas for Change

Learning about developmental disability: a medical student's perspective

Celisse Bibr, Dr. Shelley Watson, Dr. Kelly Harding, Dr. Sylvie Larocque, Dr. Diana Urajnik

Laurentian University

Article to be submitted to the Journal on Developmental Disabilities

Learning about developmental disability: a medical student's perspective

Introduction

In spite of the steps that have been taken to advocate for individuals with developmental disabilities (DDs) over the years (Lennox, Van Driel and van Dooren, 2015; Sullivan et al., 2011), the disparity between their needs and the care provided by the Canadian healthcare system still persists (Jones, McQueen, Lowe, Minnes, & Rischke, 2015; Lunskey, Balogh, Sullivan, & Jaakkimainen, 2014; Ouellette-Kuntz, 2005; Weiss, Lunskey, Gracey, Canrinus, & Morris, 2009; Werner & Stawski, 2012). Individuals with DDs constitute 0.5 to 3% of the Canadian population (American Psychiatric Association, 2013; Bradley, Thompson, & Bryson, 2002; Lunskey, Balogh, Cobigo, et al., 2014), and their health requirements are often invisible to the untrained eye (Lennox et al., 2015). Therefore, it is no surprise that authors call for the provision of training specific to DDs to be given to healthcare professionals (Lennox et al., 2015; Weiss et al. 2009; Weiss, Lunskey & Morrin, 2010; Werner & Stawski, 2012).

Canadian medical schools are responsible for preparing their students for their future role as a physician. However, students report feeling that their training in DDs is inadequate, leaving them feeling underprepared to care for these individuals (Jones et al., 2015; Weiss, Lunskey, & Morin, 2010; Werner & Stawski, 2012). As a result, medical education is currently in a “negative self-perpetuating cycle of poor training leading to the poor treatment of individuals with DD and then to more poor training for the next generation” (Werner & Stawski, 2012, p. 301).

This basic interpretive study (as defined by Merriam, 2009) explores the state of learning about DDs from the point of view of undergraduate medical students at the Northern Ontario School of Medicine (NOSM) through attempting to answer the question: what is the NOSM student experience in learning about developmental disabilities? The perspective of these future

physicians is not only valuable, but necessary, as medical students are the individuals who will experience any curricula changes that may be implemented in the future. This study explores the perspective of students within the context of being socially accountable to the communities that these future physicians will serve; as NOSM places a strong emphasis on their social accountability mandate (Strasser, 2016; Tesson, Hudson, Strasser & Hunt, 2009), this school aligned well with the goals of this study. In addition, as part of being socially accountable “includes an increased emphasis on familiarizing students with marginalized populations” (Tesson et al., 2009, p. 162), addressing the needs faced by individuals with DDs is especially relevant to medical education in this context. By examining the current state of learning about DDs in medical education, this study aims to address the health disparities currently experienced by individuals with DDs in Northern Ontario.

Materials and Methods

Undergraduate medical students were recruited from all years of schooling (not including residents) and from both NOSM campus locations (i.e., Lakehead University and Laurentian University). An ethics application was approved by the Laurentian University Research Ethics Board, Ontario, Canada, which is in accordance with the Canadian Tri-Council Recommendations for Research with Human Participants (REB#6009963).

Students were invited to participate in semi-structured interviews, conducted online through video chat services such as Zoom and BlueJeans, which took approximately 30 minutes to one hour. These interviews were informed by basic interpretive inquiry, wherein researchers are interested in how students made sense and meaning of a particular topic (Merriam, 2009): in this case, DDs. Interviewers had a semi-structured interview guide as used in previous studies (Coons, Watson, Yantzi, Lightfoot & Larocque, 2017a; Coons, Watson, Yantzi, Lightfoot &

Larocque, 2017b) and underwent training to standardize interviews between them. An example of one of the questions within the interview guide is: “How do you think your program of study/training is set up to take care of individuals with intellectual or developmental disabilities?”

Data were analyzed using thematic analysis, as detailed by Braun and Clarke (2006). All interviews were transcribed, with initial ideas being noted. Pseudonyms were used for all participants, as well as individuals (e.g., students, faculty) mentioned in the context of the interviews. Recruitment of participants was considered completed once ‘data saturation’, described by Saunders and colleagues (2018) as “identifying redundancy in the data, [...] distinct from formal data analysis” (p.1896), was reached. Once familiarized with the data, initial codes for potential themes and patterns were generated. These codes were collated into themes, which were then reviewed with respect to each other, the entire data set, and the initial research question. Once the themes were finalized, they were named, clearly described, and integrated to tell the story of the data set (Braun & Clarke, 2006). In order to ensure the accuracy of these themes, they were discussed with other researchers as well as the participants themselves. Member checking was employed both during the interview process (through summary and repetition of the interviewer’s interpretation of what was being said) and afterwards, when participants were provided with the themes, descriptions, and accompanying quotes for their assessment; all participants responded positively and gave their approval. In keeping with this transparency, an audit trail was also kept throughout the study, with all major decisions being documented (such as quote selection and theme modification).

Results

Participants included two first-year (Olivia and Morgan), four third-year (Felicia, Joshua, Sophie, and Cynthia), and two fourth-year (Anna and Maria) students. As such, eight individuals in total completed the interviews, with participants being mostly female ($N=7$). Throughout the interviews, three themes emerged: the nature of learning about DDs, barriers to learning from a student's perspective, and ideas for change.

Theme #1: the nature of learning about DDs. Experience with individuals with DDs was noted as essential for learning effectively about this topic, even if those experiences take place outside a medical setting. That said, student learning about DDs tends to begin in their third year of medical school, when NOSM transitions from didactical learning to more experience-based learning. NOSM places a heavy emphasis on learning through experience, and therefore, there is little formal curriculum around DDs directly.

DD's place in the NOSM curriculum: *"I think the amount of formal curriculum around [developmental disabilities] is... pretty lacking".* The NOSM curriculum is broken up into the first two years, with Case-Based Modules focusing on specific body systems, and the second two years, which consist of clerkship (Lanphear & Strasser, 2008; Strasser, 2016). Anna described the first two years as "mostly didactical", as each module is conducted mainly through small group facilitated sessions, known as Case-Based Learning Sessions (CBL) and Topic Oriented Sessions (TOS; Lanphear & Strasser, 2008). Felicia explained:

I can't remember if it was a TOS or a CBL, but one of the two had half of that session dedicated—like of the whole year, of anything we learnt—to developmental disabilities. And [...] the other half was something equally important, [...] just two big topics, and then we'd have weeks and weeks about sort of very similar topics.

Although the first two years of medical school are mostly didactical, this session represents the extent of formal curriculum around DDs in this period of time. As a result, Cynthia believed that “there’s a lack of education about developmental disabilities in the first two years, really.” Structured learning about DDs mainly takes place in third year, during which students have a Virtual Academic Round (VAR), where they are brought together in small groups to discuss assigned topics (Ross et al., 2014). Students agreed that this VAR was their main source of structured learning around DDs. Cynthia emphasized that although this VAR was “a good introduction”, that “introduction to this topic earlier in the curriculum would be helpful.” As it is, outside of this VAR, the vast majority of learning about DDs occurs through the students’ practical experience and beyond this VAR, students reported receiving no formal instruction on DDs.

Experience as an effective teaching tool: “*I don’t think anyone can teach it better to you than the patients themselves*”. Possibly as a result of the lack of formal curriculum, students cited their practical experiences as their main source of education about DDs. Students overwhelmingly stressed the importance of this insight. As Anna explained:

I saw a lot of [children with developmental disabilities] in paediatrics, both in my core rotation and in an elective I did here after second year. And all I can say is wow—you have no idea how many children have [...] developmental disabilities [...] Until you work with that population, you really have no idea.

All participants specified that exposure to individuals with DDs was a vital part of their learning. Interestingly, although formal training was emphasized as important, participants agreed that experience was not only effective, but essential for learning to be successful. Maria explained:

I'll be honest, I really dislike it when they just give us guidelines to read, because I'm bad at memorization [...] If I don't have it to apply to a patient [...] I'm not going to remember. [...] I think [...] exposure, just having conversations not only with patients of varying ages [...] but also talking to families [...] especially in those young kids. [...] My ideal curriculum would definitely have exposure with patients.

Hands-on training was also credited with being a major source of comfort for students when working with individuals with DDs. As Morgan explained:

I don't think, if I hadn't have gotten that experience, [...] at this point in my life I would feel that comfortable. And I think it's honestly just from experience and actually being engaged with individuals with disabilities.

Students, such as Joshua, who actively admitted to not being at the point where he could meet the needs of someone with a DD, also stated that experience would be the best way to help them to feel prepared to work with these individuals in the future. However, this statement brings to light another question: what is actively preventing students, such as Joshua, from feeling that they have the knowledge and the skills to care for someone with a DD?

Theme #2: barriers to learning. Students cited two main barriers to learning about DDs, both of which could prevent a student from gaining the skills they need to care for an individual with a DD in the future. An emphasis on learning through experience brings many benefits, but learning in a clinical setting means that learning occurs by chance: students learn what walks through the door, and have little structured curriculum to support learning on what does not occur in practice. In addition, the nature of medicine means that information is always growing, changing, and evolving. With the vast amount of learning medical students are already expected to undergo, finding a way to increase student learning without overloading them to the point of

burnout is a challenge medical education already faces (Pololi et al., 2017).

Inconsistencies between student experiences: “everyone’s exposure at NOSM is variable, depending on a series of factors”. As the majority of student learning occurs during clerkship in the latter two years of medical school, this learning will vary depending on where students are placed. As Maria explains:

My exposures there were completely different than my classmates [...] there’s pros and cons to every site [...] there’s certain conditions that I’m like “I’m hearing these words for the first time.” [...] Just because I’ve never run into a patient with it, or it’s never come up in a conversation, or I never went down that tangent in my studying. [...] You can definitely learn a lot about the patients that you’re seeing [...] but then, there are definitely gaps in my knowledge that I don’t even know are there.

As a result, opportunities for learning are not consistent between students, and student learning is, as Maria calls it, “luck of the draw”. Cynthia explains that although students “will probably run into this type of scenario somewhere [...] along the course of [their] placements”, the “curriculum itself doesn’t have any solid opportunities” for being exposed to DDs. There is an emphasis on self-directed learning in the curriculum, and students research the topics they are exposed to in their placements; therefore, disparate exposures between students results in disparate learning between students. The idea that students will “probably run into this type of scenario” also implies that they may not: there is no guarantee that students will gain the level of expertise required to feel prepared to care for someone with a DD. The solution is not as simple as to simply research DDs alongside everything else; students are already splitting their time between topics, and adding to their research often means sacrificing another topic of learning.

Information overload: “we can’t really remember everything”. Medical education

provides students with an overwhelming amount of information. As Joshua put it: “it’s all I can do to keep up with reading about the stuff I saw today [...] I definitely do need to read up on [DDs]. Put it in the long list of things that fit that category though, right?” In a similar vein, Maria explained that “the perils of medicine now is that we can’t really remember everything. So it’s more like look it up depending on who comes through the door that day. So I would Google it, let’s be real.” This also calls into question the credibility of sources that students might be attaining knowledge from, and the inconsistencies between them.

As a result of the constantly growing wealth of information, not only can students not learn it all, but the NOSM curriculum cannot fit it all. As Anna explains:

There are so many things nowadays that doctors need to know about [that] medical school would have to be like 8 years long in order to accommodate everything, [...] So, it’s difficult to accommodate all the changes that are happening and all the conditions that you need to be aware of, especially as a primary care physician. [...] I have no idea how any more information could be accommodated into the curriculum without sacrificing something else.

These two barriers to learning are strong, and not necessarily NOSM-specific. Clerkship and residency are widely accepted methods of using experience to train medical professionals, and the ever-growing state of medical information is a barrier all health-related professions face. As such, it is crucial that these barriers are dealt with, and the participants of this study had a number of suggestions as to how this could be done.

Theme #3: student solutions and ideas for change. A theme among all participants was their desire to learn more about DDs, in spite of the barriers that they face to doing so. As such, participants were more than willing to brainstorm solutions and ideas for change. With the need

to keep a balance between topics already covered within medical school, simply adding more to the curriculum is not an option—therefore, the participants put forward a number of ideas on how to increase their learning without increasing the burden on students. The three ideas that emerged were: (1) enhanced opportunity for exposure, (2) supplementing experience, and (3) acquiring knowledge from different sources.

Enhanced opportunities for exposure: “just in general, more opportunities for [exposure] to happen”. Currently, the opportunity to gain experience in the area of DDs is not consistent between students. However, participants in this study noted the fact that direct exposure to individuals with DDs is essential for effective learning about this topic. Therefore, finding ways to balance and guarantee exposure to DDs between students would go a long way to enhancing their learning. All participants asked for more exposure in general, but students also had specific ideas, such as a medical student-specific Best Buddies program that paired a student with an individual with a disability, or bringing in examples from the community, whether it be through a standardized patient, an example from the media, or a person with a disability coming in for a guest lecture. In addition, Maria proposed an idea for equalizing student experience by tailoring exposures:

I think potentially having a questionnaire or something, like in first year [regarding] where [does] your experience lie in all these different areas. We’d probably tailor those interprofessional exposures a little bit more. There’s people in my class who were nurses. They don’t need to spend more time with nurses. They’re good, they get it. Me, on the other hand, I need to spend more time with nurses to understand what nurses do. So, I think the school does a pretty good job, but layering and [using] those screeners of where people need more exposure might help a bit more.

By taking into consideration student experience prior to medical school, their education could not only begin with their baseline knowledge in mind, but could move forward to account for their different areas of expertise (or lack thereof). This consideration would also allow for additional learning opportunities regarding DDs to be added within the curriculum without taking away from what is already there, or putting further strain on students.

That said, although experience is an effective method of learning about DDs, it is not the only way. Within NOSM's self-driven learning model, students are expected to supplement their learning mainly through their own research. However, as students tend to research topics that are being brought up in their clinical experiences, this may be adding to the gaps in knowledge, as opposed to accounting for them.

Supplementing experience: "in retrospect [...] I would've liked a few more lectures on things". Experience was acknowledged as crucial to learning about DDs by the participants of this study. However, not all students get the opportunity for these experiences, and in these cases, it is important that medical schools implement structured learning to make sure students still get essential information. As Maria explains:

I think one thing that would strengthen NOSM is, especially early on, laying the groundwork for the basic sciences, and then building up on it [...] and then shifting into more of the self-directed. Because honestly, starting medical school and getting a textbook list and being like, "Yeah, you write exams every six weeks." You're like, "Wait, what? No. Teach me, please." [...] I think we get more lectures in fourth year than we do all other years combined [...] I love all my lectures now, it's really helping studying for the licensing exam. But I definitely would have liked them earlier on too. In the same vein, all participants expressed their wish to see training on DDs in the

curriculum during first and second year, when teaching is more didactical, in order to build a base that students can work from when doing their own research. In particular, students wished for a centralized place to find resources both for themselves and for patients. Supplementing experience through formal curriculum also allows for the exploration of topics that experience may not help with; for example, the transition from child to adult care for individuals with DDs. As Sophie explains, “that transition seems to be where a lot of people get lost”, and accounting for it is an area where the healthcare system currently struggles (Crowley, Wolfe, Lock, & McKee, 2011). As students may not be getting effective strategies on how to properly account for this transition, this is an area where medical school’s formal curriculum could make a difference: not only in the students’ learning, but in the patients’ care in the future. This structured learning does not necessarily have to be in typical lecture format; participants in this study expressed a desire to learn from different sources, such as individuals within the community with DDs, or individuals who work with those who have a DD. This support would allow for a compromise between learning from experience and learning from formal curriculum.

Acquiring knowledge from different sources: “I think there [are] so many wonderful people out there who [...] have so much information to share”. Participants stressed the importance of an interdisciplinary team-approach to caring for individuals with DDs, and would like to see that reflected in their education. Students expressed a desire to connect with individuals involved in community services such as group homes, law enforcement, and education. Felicia mentioned having a paediatric resident educate students, as “I find that often residents just understand the student context and what is important—like what we probably understand at this point, and what they found helpful to learn these tools”. Other students, such as Morgan, were already pushing initiatives forward:

I've been pushing to have a physician come in to talk to us about modifying clinical practices for individuals with developmental disabilities, and no one's really seemed that interested in it. I'm sure part of it is [because] I'm so interested in different disabilities [and] how to deal with [them] in a clinical setting. I spoke to a paediatrician at [a conference] who was telling me about all the things she's done to modify her practice for children with disabilities.

Attaining knowledge from people in the community, people with DDs, caregivers, or other trained professionals would allow students to gain a holistic education on how to care for individuals with DDs.

In summary, NOSM student learning about DDs occurs mainly in their third year of education, and students agree that formal training is limited. Most learning occurs through experience, but as this experience occurs through clerkship, opportunities for learning about DDs are inconsistent between students and are not necessarily guaranteed. A separate barrier to learning about DDs was the state of medical knowledge: both the curriculum and the students are already overwhelmed with topics to learn, and there simply is not enough time to adequately fit everything into the formal curriculum. However, the students who participated in this study were brimming with solutions, with most ideas encompassed in one of the following areas: an idea to enhance opportunities for exposure, to supplement their experience, or to acquire this knowledge from different sources.

Discussion

The disparity between the health needs of individuals with DDs and the care provided to them by the Canadian healthcare system has persisted over the years (Jones et al., 2015; Lunskey et al., 2014; Ouellette-Kuntz, 2005; Weiss et al., 2009; Werner & Stawski, 2012). Medical

schools are responsible for preparing students as physicians for the population they are serving, and individuals with DDs are no exception. The role of experience in preparing medical students is one that has endured for centuries (Yardley, Teunissen, & Dornan, 2012), and is especially prevalent in the latter years of medical education, through clerkship and residency. NOSM has a longitudinal clerkship, starting with the Comprehensive Community Clerkship (CCC) in the students' third year, and continuing through the students' fourth year (Strasser et al., 2013). The school aims to have a clerkship such that "the curriculum walks through the door" (Strasser et al., 2013, p. 3). In theory, this is effective; participants in this study agreed that experience was essential for learning about DDs. However, medical education's emphasis on learning in context, especially in latter years, also results in a barrier to learning about topics such as this: between students, opportunities for learning are inconsistent, unequal, and often up to chance. Not everything walks through the door, and, as a result, as Maria put it: "there are definitely gaps in my knowledge that I don't even know are there."

Students proposed many solutions and ideas for change. Supporting learning opportunities, whether it be through simply providing more of them, supplementing learning through formal curriculum around DDs, or providing knowledge from different sources (e.g., an individual with a DD or their caregiver) could help to fix gaps in knowledge. Support could also be provided through preceptors; with medical education's emphasis on learning through experience, it is illogical to expect healthcare practitioners, and students in the future, to teach essential knowledge with no teaching training (Nagji et al., 2017). Providing teaching training while in medical school could also prepare students for their roles as teachers in the future (Nagji et al., 2017).

Another solution, proposed by Maria, a fourth-year student, involved considering the

diverse backgrounds and experiences of students prior to medical school. Students enter medical education with different undergraduate degrees, employment backgrounds, and volunteer experiences. For example, Maria cited her classmates that worked as nurses before coming to NOSM; these individuals are less likely to require further learning opportunities regarding the importance of an interprofessional team in comparison to other students who do not have this experience. By tailoring the distribution of learning opportunities to account for student backgrounds, experiences between students could be equalized.

The other barrier to learning about DDs involves the nature of medical education. The literature is constantly growing, changing, and adapting; as future physicians, medical school students are expected to keep up with all advancements in medicine. However, with the ever-growing state of medical literature, this is simply no longer feasible. There is not enough time in the curriculum, nor in a student's day, to cover every single health-related topic, and student burnout is already prevalent to a concerning degree in medical school (Pololi et al., 2017). The mental state of students is essential to keep in mind when making changes to the curriculum, as the state of the physician will affect the state of the patient (Pololi et al., 2017).

These findings are based on the perspectives of eight participants; therefore, this study is limited mainly by their individual characteristics. Only one participant identified as male, and only students from the Laurentian University campus participated, although all efforts were made to recruit from both campuses. In addition, participation was voluntary, meaning that students were more likely to participate if they had an already existing interest in DDs. Therefore, aspects such as students' desire to learn more about DDs may not be representative of other NOSM students. However, member checks were conducted with participants to inform them of the emerging results of this study; the final thematic results presented here are consistent

with the perspectives of the small portion of students that were interviewed.

That said, this study brings forward valuable student perspectives. The barriers that these students are experiencing are not unique to them; students are already experiencing burnout (Pololi et al., 2017) and experiential learning is an emphasized part of medical education through clerkship and residency (Yardley et al., 2012). Initiatives to address the overwhelming aspect of medical knowledge and the disadvantages to learning through experience would not only help student training specific to DDs, but students' medical training across the board. The students within this study were brimming with ideas and solutions for change; future studies should not only explore these ideas, but combine them with the ideas of students from other schools, residents, currently practicing healthcare professionals, and recommendations from other research. A starting point could build from the primary care guidelines developed for Canadian healthcare professionals in caring for individuals with DD; as of the 2006 guidelines, it was recommended that there be a minimum of 22 hours of DD-specific training across all Canadian medical schools (Sullivan, as cited in Burge, 2007; Sullivan, 2006). More recently, these guidelines have been revised (Sullivan et al., 2018); working alongside these guidelines and consulting these experts could be beneficial in adding to the curriculum surrounding DDs. In addition, studies such as Lennox et al. (2015) describe several initiatives to improve healthcare provider knowledge that Canadian medical education could take from (e.g., the Colleges of General Practitioners in the United Kingdom and Australia have health curriculums specific to DDs), but end on the note that the effectiveness of programs and guidelines need to be evaluated. Finding an innovative, adaptive solution to addressing topics that are not yet adequately covered in all medical education, such as DDs, would have wide-ranging benefits all across Canadian healthcare systems; future research should generate and evaluate these solutions in order to

provide the best possible healthcare to individuals in Canada.

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Chapter 4: Discussion

4.1 Summary of Research Findings

One of the main sources of information from which healthcare professionals report gaining FASD knowledge is medical school (Coons et al., 2017; Payne et al., 2011b), and the PHAC (2005) calls for the periodic monitoring of their knowledge in order to support individuals with FASD. This thesis serves this purpose by beginning with the literature on currently practicing healthcare professionals (Anderson et al., 2010; Coons et al., 2017; Payne et al., 2011a; Payne et al., 2011b; PHAC, 2005) and taking a step back to explore their knowledge during their time in medical school. NOSM students were particularly well-suited for this study, as the school's social accountability mandate "includes an increased emphasis on familiarizing students with marginalized populations" (Tesson, Hudson, Strasser, & Hunt, 2009, p. 162). As individuals with FASD fall under this category, the results of this study are of particular importance to NOSM.

The main findings of this thesis involve: (1) the knowledge the NOSM students hold in regards to FASD and its surrounding topics; and (2) the students' experiences in learning about developmental disabilities. Participants in both phases demonstrated general knowledge about FASD. Students knew of the disorder, that it is associated with prenatal alcohol consumption, and knew that it was associated with certain neurocognitive and physical manifestations. However, as Felicia (third-year student) put it: "I can't really tell you exactly what they are". This lack of knowledge regarding the specifics of FASD is replicated in literature regarding currently practicing healthcare professionals (Anderson et al., 2010; Payne et al., 2011a; PHAC, 2005). While these results are unsurprising, given the complexities of the disorder, they imply

that medical education is not currently accounting for the gaps in knowledge that have already been identified in the literature.

In a similar vein, although students believed FASD guidelines for diagnosis existed, the vast majority of Phase I participants were unaware of what they were. Students in Phase II elaborated that they would know where to search for these types of guidelines, and some students had: two participants alluded to the new guidelines through referencing the fact that “the name [had] sort of changed over time” (Anna, fourth-year student) and referencing the health watch table by Surrey Place (Sophie, third-year student), which does reference the new Canadian guidelines (Cook et al., 2015; Tao, Temple, Casson, & Kirkpatrick, 2013). Interestingly, two students (Morgan and Olivia; first-year students) used the term FAS without prompting, but no students mentioned FAE, ARND, ARBD, or pFAS. Morgan explained that she “would use [Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder] interchangeably”. This may be connected to the findings of the Public Health Agency of Canada (2005), as previously discussed, where Canadian healthcare providers held more knowledge about FAS than the other disorders along the FASD spectrum at the time. In addition, most Canadian clinics are still using the 2005 guidelines (Clarren et al., 2015); as NOSM students do a large amount of their learning in practice, it is likely they will be taught the 2005 guidelines, as opposed to the most recent ones. That said, the students in this study did tend to hold more knowledge regarding diagnosis versus the treatment of FASD.

This general understanding of FASD extended to its surrounding topics, as well, such as the use of alcohol during pregnancy. The mechanisms through which alcohol causes cognitive deficits are diverse (Goodlett et al., 2005; Pretrelli et al., 2018) and therefore there is no clear answer as to which FASD outcomes correspond to different timing or levels of alcohol

consumption during pregnancy (Day et al., 2013; Laufer et al., 2013). It has even been reported that alcohol consumption is associated with positive outcomes for the newborn (Kelly et al., 2008). Students' advice to clients directly suffers as a result of this conflicting, unspecific knowledge. Participants in Phase II particularly struggled with the situation of a pregnant individual who had consumed alcohol before they knew of their pregnancy. In this case, students struggle between wanting to reassure their client and not wanting to give them false information. However, as there is no definite answer as to when a child will develop FASD, students are often left feeling frustrated, and unable to properly advise their client. Some students, such as Felicia, were hesitant to even mention the possibility of FASD at this point, as they are already dealing with the unexpected news of their pregnancy.

This hesitation links to the next point of the first paper: students' knowledge of FASD directly influences their comfort levels, or their perceived level of competence. If students do not feel they hold the appropriate knowledge, or if they feel their knowledge is conflicting (like the literature around alcohol use during pregnancy so often is), they do not feel confident to advise clients in these scenarios. As a result, it is no surprise that the majority of participants in Phase I reported feeling unprepared to care for individuals with FASD, pregnant women, birth mothers, foster parents, and adoptive parents in the area of alcohol dependency. These findings support those of currently practicing physicians, who also feel underprepared to care for these clients (Payne et al., 2011a; PHAC, 2005; Tough et al., 2005a). However, physicians do feel more prepared to access resources for these clients than to directly care for them (PHAC, 2005), as do the medical students in this study. That said, the majority of participants still did not feel ready to access resources for foster parents, adoptive parents and individuals with FASD in this area. This alludes to Phase II, which elaborated on these results: in general, students in this study reported

feeling more comfortable with advising clients around alcohol use during pregnancy, as opposed to diagnosing, treating or informing patients specifically on the topic of FASD. This does not indicate they are necessarily comfortable with advising clients around alcohol use during pregnancy: it only highlights how uncomfortable students are with the topic of FASD directly. Collecting information regarding alcohol intake during pregnancy is relatively routine for practicing physicians (PHAC, 2005); however, as of now, the topic of FASD is not part of that conversation.

One important way of increasing knowledge and comfort levels is through learning through experience. Exposure to individuals with FASD, and developmental disabilities in general, was an important theme throughout Phase II; participants overwhelmingly stressed the importance of real-world learning about developmental disabilities. Morgan directly stated that if she “hadn’t have gotten that experience” with individuals with developmental disabilities, that she did not think that “at this point in my life [she] would feel [this] comfortable”. It is possible that this emphasis on exposure is a result of NOSM’s emphasis on learning in context; in fact, the school has directly structured their program such that “the curriculum walks through the door” (Strasser, 2016, p. 3), as seen through their Comprehensive Community Clerkship (CCC) during the students’ third year (Strasser, 2016). It is during this third year where FASD appears in the NOSM curriculum; participants in Phase II described their Virtual Academic Round (VAR) on developmental disabilities, which involves students being brought together to discuss cases based on specific learning objectives (Ross et al., 2014), during which one of these objectives was FASD. The case-based learning strategy (CBL) that VARs are based upon has very positive reviews; the usage of this strategy is perceived to engage and motivate students, thereby enhance their learning (Thistlethwaite et al., 2012). Students also report enjoying this

type of learning (Thistlethwaite et al., 2012). VARs differ from traditional CBL as, according to NOSM's self-directed learning model, students research topics and teach each other through these VARs with faculty taking the role of a facilitator, as opposed to a teacher (Ross et al., 2014). In this case, the VAR on DDs was "a good introduction" (Cynthia, third-year student) to the topic of FASD; however, this is the extent of the structured learning on this topic, and it is student-driven.

The barriers to learning about developmental disabilities, and therefore FASD as well, identified in this study may be due to the emphasis on self-driven and experiential learning. The result of learning what "walks through the door" (Strasser, 2016, p. 3) is an education that is, as Maria puts it, "luck of the draw". Students are not on the same placements, and students are not seeing the same patients, and, as a result, the first barrier to learning arises: inconsistencies between student experiences. At the same time, the self-directed learning model relies on students' taking charge of their own education. Students have an endless supply of ever-changing information at their fingertips: the second barrier to learning comes into play when this information comes with the expectation that future healthcare practitioners must know it all (Achike & Ogle 2000). It is also exacerbated by the self-directed model of learning; the pressure of not only learning all topics, but knowing what topics to learn, is all on the students' shoulders. This is particularly problematic for topics that students are unaware of, and do not see (or identify) in practice; as Maria put it: "there are definitely gaps in my knowledge that I don't even know are there." The combination of levels of experience that are inconsistent between students, and an overwhelming amount of information that students are expected to learn, make the experience of learning about specialized topics, such as FASD, very challenging. Medical school curricula are already filled with topics of learning. Finding a way to incorporate more

knowledge, equally across all students, without sacrificing another topic or increasing the already high rate of burnout in medical students (Pololi et al., 2017), is difficult, but necessary. It is the job of those in healthcare education to continue to improve it for the sake of their students; better prepared students will result in better care for patients, and, in Canada, better care for patients with FASD and pregnant individuals using alcohol is a necessity (Clarren et al., 2011; PHAC, 2005; Phillips & Johnson, 2001).

4.2 Methodological Rigour and Study Considerations

A mixed methods study design was well-suited to this study's purpose. To begin, it strengthened the validity of the results through methodological triangulation; as the data from each phase supported the data from the other, this study design allowed for more confidence in the accuracy of the conclusions. Similarly, this accuracy was also assisted by the elaboration of Phase II upon Phase I; students were able to directly add their perspectives to results that would have otherwise been up to researchers' interpretation. This mixed methods design also allowed for aspects to be captured that otherwise would not have been; for example, several participants in Phase II directly described how they felt while filling out the questionnaires. On the other hand, having Phase I results as a basis to build from allowed both researchers and participants to start on the same page, with researchers have a better understanding of their participants, and participants having a better understanding of the study they were participating in. Students in Phase II were comfortable and open to discussing the strengths and weaknesses of both their education and themselves, and several participants were interested to know if a curriculum for FASD would be developed as a result of this study. This success in the interviews may also be a result of the way in which this study was framed: it was never intended to evaluate students or

NOSM itself, but to allow a reader outside of these perspectives to step into their shoes and possibly apply these results to other medical educational settings.

That said, the conversation around FASD in Phase II often turned to developmental disabilities in general, as students often did not have the FASD-specific knowledge, experiences or advice to answer interview questions. Recruitment was also particularly challenging in Phase II; although the eight participants provided a wealth of information, more interviews would have been beneficial to strengthen the themes in this study. This is also applicable to Phase II; although 24 students filled out the questionnaires, only 18 students completed them. That said, data saturation, as described by Saunders and colleagues (2018) was reached in Phase II, as evidenced by the redundancies and repetitions in the interviews. Incentives were only applied to Phase II, so it is possible that the inclusion of incentives to complete the questionnaires could help prevent dropout and increase participation. However, medical students are notoriously over-studied and, as previously discussed, have very little time in their schedules as it is. Students also alluded to the wealth of emails that they receive from day to day, and, as a result, many emails do not necessarily get read; therefore, this study also used Facebook pages to recruit, as well as the NOSM website, to increase the visibility of this study in areas other than email. More disparate methods of recruitment such as these should be explored in the future to increase participation; these particular students may have been more difficult to recruit as they not only have the challenges that medical students face, but they are also often away on their placements. It is for this reason that this study relied on electronic recruitment, and electronic participation.

Another area of recruitment that could be improved is the gender ratio. Both phases were skewed towards female participants; in Phase I, three-quarters of the participants identified as female, and Phase II only included one participant who identified as male. Similarly, the ratios

between years of study could be improved. Phase I respondents were mainly third-years ($N=12$) as opposed to year one ($N=4$), two ($N=3$) and four ($N=5$). Phase II respondents were also primarily in their third year ($N=4$), as opposed to year one ($N=2$), two ($N=0$) and four ($N=2$). Although this was not necessarily detrimental, as FASD education happened to fall in the third year of NOSM's curriculum, equalizing these ratios would help to provide a more holistic view of the student experience.

The use of online surveys and video chat services worked very well. The use of two audio recording methods (one through the video chat service, and the other through an external recording device) helped to reduce any audio errors that occurred while recording. That said, there were moments of audio and video error during the interviews due to problems with internet connectivity. However, as these were noticeable during the interviews themselves, they were easily remedied by asking the participants to repeat themselves, or to wait a moment while the internet stabilized. There was also the possibility of error in the surveys, as there were a few cases of duplicate entries (where a participant began the questionnaires, exited out, and then entered back in, thereby creating two entries for themselves). With the exception of students who agreed to participate in Phase II as part of the questionnaires (and thereby provided their contact information), identifying duplicate entries is a challenge, and not necessarily possible if the participant changes their answers. Although several of these duplicate entries were accounted for, it is possible that some may have been missed.

All in all, the use of online services served to minimize any inconvenience that participation in this study could cause students; this may have been particularly important for the recruitment of third- and fourth-year students, as well as those on the campus of Thunder Bay. However, all participants in Phase II were attending NOSM's Sudbury campus; this may be due

to the fact that it was not made clear, in the questionnaire itself, that Phase II interviews would take place online (see Appendix C), although this information was available in the recruitment emails and posts. As even some participants who agreed to Phase II asked how the interviews would be conducted, making this information more readily available to these students could be beneficial for enhancing recruitment.

One particular limitation of this study, connected to recruitment, is that of priming. Students were informed that this study was on the topic of FASD, and therefore, students were primed to view alcohol in a negative light when participating in this study. This may have influenced answers to questions such as those that asked about standard levels of alcohol consumption. As participation was voluntary, students with an existing interest in FASD, or developmental disabilities in general, may have been more likely to participate in this study. Therefore, the group of students who participated in this study may not necessarily be representative of the larger population of students. In other words, taking into consideration self-directed learning, students with an existing interest in developmental disabilities may be more likely to hold more knowledge on this topic, have experiences in this field, and feel more prepared to care for these patients. This is supported by the results of Phase II, where all participants had had some sort of experience with individuals with developmental disabilities, often volunteer positions. In addition, rural and Northern areas are unique in many areas; as previously discussed, FASD is one of them. Rural areas tend to report higher prevalence rates of FASD when compared to urban areas (Tough et al., 2008a; Coons et al., 2017). Possibly as a result, rural healthcare providers are more likely to engage in conversation about the risks of alcohol use during pregnancy to women of child bearing age and are more likely to report feeling prepared in caring for mothers who are using or dependent on alcohol when compared to their

urban counterparts (areas (Tough et al., 2008a; Coons et al., 2017). As a result, the findings of this study may not be representative of medical schools outside of this type of setting.

Although they may not be representative of larger populations, the perspectives of the student participants are still valuable, and it is important to make sure they are accurate. All interviews were conducted by two researchers, both trained to standardize the interviews between them. Themes were not only discussed with other researchers, but also with the participants through the process of member checking. Participants were provided with the themes, descriptions, and accompanying quotes for their assessment; all participants responded positively and gave their approval. In keeping with this transparency, an audit trail was also kept throughout the study, with all major decisions being documented. For example, there are separate documents that contain all quotes that correspond to codes, quotes that correspond to preliminary themes, and quotes that correspond to finalized themes; the rationale for theme modification has also been detailed, along with their selection in the first place.

The interviews were also successful through the use of vignettes. As much of NOSM's formal curriculum is through case-based learning, students were comfortable with and ready to react to the vignettes. These reactions allowed for deeper exploration of student perspectives; for example, participants reacted particularly strongly to Vignette #3 (where the physician advises their pregnant patient to have a few drinks to react), and Vignette #4 (involving a pregnant individual with FASD) allowed for students to elaborate on the any hesitation or confusion they may have had around the topic (in particular, this is where the question of a genetic component of FASD came up).

All in all, this study worked well to answer the research question that was proposed. A mixed methods design was a good fit, and resulted in a thorough understanding of the

participants' perspectives. The limitations of this study provide an opportunity for future research to build on the basis provided here.

4.3 Real-World Implications and Future Directions

The major implication of the first paper in this thesis is further exploration as to why the diagnosis of FASD is often delayed or not considered (Chudley et al., 2005): namely through a ripple effect. The lack of strong, specific knowledge surrounding this topic may lead to future healthcare practitioners feeling unprepared to care for clients in this area. This is already a finding in currently practicing physicians (Payne et al., 2011a; PHAC, 2005; Tough, Clarke, Hicks & Clarren, 2005a), and the results of this study imply that this issue may date back to medical school. The ultimate result of this lack of preparation is the aforementioned hesitation to have the discussion about FASD, which is especially important as for a diagnosis of FASD to be assigned, it is essential to have the knowledge of confirmed alcohol exposure (Cook et al., 2015) and early diagnosis is one of the strongest protective factors against the secondary impacts of FASD (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004). Having a healthcare practitioner who is knowledgeable about and comfortable with the topic of FASD could allow for the reduction of stigma around the topic, the correction of any misconceptions around alcohol use or FASD itself, and allow for patient to be proactive in their child's care in the future.

The other implication of the first paper is that students are not necessarily learning about the new Canadian guidelines for FASD diagnosis (Cook et al., 2015). This is especially problematic as most Canadian clinics are still using the 2005 guidelines (Clarren et al., 2015): if currently practicing physicians are not using the 2015 guidelines, and future physicians are not necessarily learning the 2015 guidelines, how will they be implemented in practice? The issues around FASD and alcohol use during pregnancy are complex enough without adding conflicting

information regarding diagnostic criteria to the mix: major changes such as these need to be well documented and well-advertised.

The second paper discussed in this thesis has two main practical implications, and those are the barriers to learning as identified by the participants. Students have little formal curriculum around developmental disabilities, and the focus on learning through experience results an education that is not always consistent between students. As a result, these future physicians may have inconsistent levels of expertise on this subject; this directly links back to the students' overall feeling of hesitation to care for these clients. The participants of this study report feeling underprepared to care for individuals with FASD, and this feeling is replicated in the literature (Payne et al., 2011a; PHAC, 2005; Tough et al., 2005a). As a result, clients feel under-supported (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Ryan, Bonnett, & Gass, 2006; Salmon, 2008; Sanders & Buck, 2010; Watson, Hayes, Coons, & Radford-Paz, 2013), and the lack of understanding and support for those with FASD may contribute to the development of further mental health problems (Phillips & Johnson, 2001). In addition, the second barrier to learning, information overload, means that both students and faculty may be struggling to find the time to fit topics such as FASD into the curriculum or learning experiences. This struggle may result in the exclusion of essential knowledge (such as that of the new guidelines), and thereby can cause a ripple effect that can lead to a diagnosis of FASD being delayed or not considered. As all medical schools are fighting similar battles, it is vital to find a solution to this problem.

This brings us to the future directions of this thesis. First and foremost, student knowledge on the subject of FASD must be addressed. The literature demonstrates that Canadian healthcare providers need more knowledge on this topic (Coons et al., 2017; PHAC, 2005), and

this thesis demonstrates that they are not necessarily getting it. This thesis also demonstrated that students desire to learn more; they are aware of their lack of preparation and would like to address it. As Joshua put it: “I definitely do need to read up on it. Put it in the long list of things that fit that category though, right?” In addition, this study recommends that students are prepared to care for clients with FASD in order to keep with NOSM’s social accountability mandate (Tesson, Hudson, Strasser, & Hunt, 2009). This is especially relevant as the reported prevalence rates of FASD tend to be higher in rural areas when compared to urban areas (Tough et al., 2008a; Coons et al., 2017).

The second paper of this study discussed various solutions to this problem that were proposed by the study participants, with a promising idea offered by Maria (fourth-year student), wherein NOSM accounted for students’ previous experience when coming in to medical school. By this, she explained that some sort of survey or questionnaire, given at the beginning of the students’ medical education to assess their background and experience in areas of medicine, could be used to tailor their learning experiences to account for any gaps in their knowledge. Other solutions, such as learning from standardized patients or bringing in individuals from the community, were also promising. Allowing students to interview a standardized patient with FASD, or being able to speak with someone who works with these individuals on a day-to-day basis, could be an effective compromise between the structure of a formal curriculum, and the hand-on experience that enhances learning.

In summary, this study proposes the following recommendations which Canadian medical schools could explore to better prepare their students to care for individuals with FASD: (1) providing not only more opportunities to work with these individuals, but enforcing methods which ensure all students have equal access to these opportunities; (2) supplementing and

supporting experiential learning through structured learning; and (3) using various sources to deliver this knowledge, whether it be community members or standardized patients, as a compromise between making sure all topics get covered through structured learning and allowing students to gain knowledge through experiential learning.

Medical education also needs to find an effective way to distribute the new guidelines; this is not the first time changes need to be disseminated throughout healthcare providers and it will not be the last. FASD-specific organizations and medical education should collaborate to make sure that future medical practitioners across Canada are receiving the latest information on this topic—this is particularly important to address in areas of Canada that do not have FASD-specific programs (Clarren et al., 2011). Enhancing student knowledge on this topic will not only enhance patient care, but it will mean these future physicians are better equipped to address complex topics such as the stigma surrounding FASD, and the misconceptions around alcohol use during pregnancy.

There are also a number of routes to go from here in terms of research. Future studies should be done with students from other medical schools across Canada to determine if these experiences are consistent across students, and if other medical schools have developed their own strategies to address these barriers to learning. Other medical schools may also have implemented a developmental disability or FASD-specific training program into their curriculum; both the design and the effectiveness of these types of initiatives needs to be explored. The data of this study could also be compared to data of students in previous years, or to students in the future, in order to investigate if knowledge surrounding FASD is improving over time. Similar studies could be conducted with currently practicing physicians, in order to not only determine their knowledge levels regarding FASD, but also determine how these levels

could be improved; practicing physicians have their own unique barriers to learning, and finding an effective method of disseminating knowledge (such as the new FASD guidelines) to them is essential. Both currently practicing and future healthcare practitioners should be consulted with in order to develop unique solutions to the challenges that medical education faces. Even in the small sample of this study, students were brimming with ideas for change and solutions to the issues they identified; getting ideas such as these on a larger scale would allow for a thorough and unique approach to solving these problems.

4.4 Conclusion

The main objective of this thesis was to explore the knowledge of NOSM students in regards to FASD, as their time in medical school will inform their future practices as physicians in Northern Ontario. In doing so, this thesis aimed to: (1) add to the Canadian FASD literature; (2) identify common misconceptions, gaps in knowledge and barriers to student learning; and (3) help inform future curricular changes in medical education. The participants in this study went above and beyond to answer these questions; they offered their perspectives, issues and ideas in order to build an accurate account of their point of view. As a result, this study is an important first step towards a strong, cohesive message from healthcare professionals and improved support for both individuals with FASD and their families, as well as pregnant individuals using alcohol.

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APPENDIX A – Recruitment Script for Students

Hello!

My name is Celisse Bibr and I am a MA student in the Interdisciplinary Health program at Laurentian University in Sudbury, Ontario. I am interested in studying the knowledge and advice of health care students regarding Fetal Alcohol Spectrum Disorder (FASD) in Northern Ontario. I would greatly appreciate your participation in this study.

Your involvement may entail participation in an individual interview with the researcher to understand what different health care professional groups know and believe about FASD, in addition to the completion of two questionnaires. This study will be conducted over two phases. Phase one involves the completion of two questionnaires, which can be accessed online through REDcap. The link to access these questionnaires is included with my business card that I have here to hand out. During phase one, you will also be asked if you would be interested in participating in phase two, which involves a semi-structured interview and a scenario-based vignette. Everyone who participates in phase two of the study will also receive a \$5 gift card for Amazon for their participation.

I am specifically looking for health care students at the Northern Ontario School of Medicine. The questionnaires will take approximately 20 to 30 minutes to complete. The interviews will last approximately 45 minutes and, with your consent, will be audio recorded. Interviews will take place at a time and location that best suits your schedule and where you feel comfortable. Both phases will ask questions about your program of study, your perceptions and belief about alcohol consumption during pregnancy, some of your personal and professional experiences, your knowledge and awareness of FASD, and health care needs in rural and Northern Ontario.

You are under no obligation to participate in this study and you may withdraw at any time without consequence. If you are tired during the interview, you may take a break or stop at any time. You may also choose not to answer any questions during the interview or on the questionnaires. It is not anticipated that this study poses any additional risks to participants that would otherwise not occur in everyday life, but if you feel distress at any time during the research, you will be free to withdraw from the research at any time. Personal information gathered as part of this study will remain private and confidential. All identifying information, such as your name, will be changed to ensure confidentiality. All questionnaire responses, interview transcripts, and audio recordings will be destroyed 5 years after the completion of this project. The research ethics board at Laurentian University has approved this research project.

If you would be willing to participate, please access the questionnaires on REDcap at the following link. Please feel free to contact, myself, Celisse Bibr, or Dr. Shelley Watson at the information provided below if you have any questions or concerns. If you choose to participate, please fill a copy of the consent form online. If you are interested in participating in phase two, please put your contact information on the consent form so that I may contact you to schedule an interview. You may also keep one copy of the consent form for yourself.

I sincerely hope that you will consider participating in this study. The information we gather will be used to identify areas within health care curricula that may need additional attention. The information we gather will also be used to improve the confidence, self-efficacy, and knowledge of future health care professionals regarding developmental disabilities and FASD.

If you have any questions or concerns about this study, please feel free to contact Celisse Bibr at cbibr@laurentian.ca, or my supervisor Shelley Watson at 705-675-1151 or 1-800-461-4030, ext 4223, or swatson@laurentian.ca. If you have concerns regarding the ethics of the study, you may contact the Research Ethics Officer, Laurentian University, at 705-675-1151 or 1-800-461-4030, extension 3213, or at ethics@laurentian.ca.

APPENDIX B – Recruitment Script for Students (via e-mail)

Hello!

My name is Celisse Bibr and I am a MA student in the Interdisciplinary Health program at Laurentian University in Sudbury, Ontario. I am interested in studying the knowledge, and advice of health care students regarding Fetal Alcohol Spectrum Disorder (FASD) in Northern Ontario. I would greatly appreciate your participation in this study.

Your involvement may entail participation in an individual interview with the researcher to understand what different health care professional groups know and believe about FASD, in addition to the completion of two questionnaires. This study will be conducted over two phases. Phase one involves the completion of two questionnaires, which can be accessed online through REDcap. The link to access these questionnaires is included below at the bottom of this e-mail. During phase one, you will also be asked if you would be interested in participating in phase two, which involves a semi-structured interview and a scenario-based vignette. Everyone who participates in phase two of the study will also receive a \$5 gift card for Amazon for their participation.

I am specifically looking for health care students at the Northern Ontario School of Medicine. The questionnaires will take approximately 20 to 30 minutes to complete. The interviews will last approximately 45 minutes and, with your consent, will be audio recorded. Interviews will take place at a time and location that best suits your schedule and where you feel comfortable. Both phases will ask questions about your program of study, your perceptions and belief about alcohol consumption during pregnancy, some of your personal and professional experiences, your knowledge and awareness of FASD, and health care needs in rural and Northern Ontario.

You are under no obligation to participate in this study and you may withdraw at any time without consequence. If you are tired during the interview, you may take a break or stop at any time. You may also choose not to answer any questions during the interview or on the questionnaires. It is not anticipated that this study poses any additional risks to participants that would otherwise not occur in everyday life, but if you feel distress at any time during the research, you will be free to withdraw from the research at any time. Personal information gathered as part of this study will remain private and confidential. All identifying information, such as your name, will be changed to ensure confidentiality. All questionnaire responses, interview transcripts, and audio recordings will be destroyed 5 years after the completion of this project. The research ethics board at Laurentian University has approved this research project.

If you would be willing to participate, please access the questionnaires on REDcap at the following link.

[Insert link here]

Please feel free to contact, myself, Celisse Bibr, or Dr. Shelley Watson at the information provided below if you have any questions or concerns. If you choose to participate, please fill a copy of the consent form online. If you are interested in participating in phase two, please put

your contact information on the consent form so that I may contact you to schedule an interview. You may also keep one copy of the consent form for yourself.

I sincerely hope that you will consider participating in this study. The information we gather will be used to identify areas within health care curricula that may need additional attention. The information we gather will also be used to improve the confidence, self-efficacy, and knowledge of future health care professionals regarding developmental disabilities and FASD.

If you have any questions or concerns about this study, please feel free to contact me at cbibr@laurentian.ca, or my supervisor Shelley Watson at 705-675-1151 or 1-800-461-4030, ext 4223, or swatson@laurentian.ca. If you have concerns regarding the ethics of the study, you may contact the Research Ethics Officer, Laurentian University, at 705-675-1151 or 1-800-461-4030, extension 3213, or at ethics@laurentian.ca.

APPENDIX C – Health Care Student Questionnaire

As a health care professional in training, you are invited to participate in this study. We will ask you to answer questions about your knowledge and experiences regarding individuals with developmental disabilities in general, as well as individuals with Fetal Alcohol Spectrum Disorder. In addition, we will ask you about your experiences and beliefs about learning. You do not have to answer all questions if you do not want to. You can also discontinue your participation at any time without penalty.

The questionnaires will take approximately 20-30 minutes to complete.

Would you also be interested in participating in a semi-structured interview about your experiences as a health care student in relation to developmental disabilities and fetal alcohol spectrum disorder? You will receive a \$5 Amazon gift card for your participation in this interview. If yes, please indicate below and provide your contact information.

No Yes

Name: _____

E-mail Address: _____

Phone Number: _____

We would like to begin by asking a few questions about you.
<p>1. What is your gender?</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Female</p> <p><input type="checkbox"/> Transgender</p> <p><input type="checkbox"/> Prefer not to answer</p>
<p>2. What is your age? _____ years</p>
<p>3. What is your current program of study?</p> <p><input type="checkbox"/> Undergraduate medicine (Sudbury)</p> <p><input type="checkbox"/> Undergraduate medicine (Thunder Bay)</p> <p><input type="checkbox"/> Nurse-practitioner</p> <p><input type="checkbox"/> Midwifery</p>
<p>4. What year of the program are you in?</p> <p><input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4</p>
<p>5. What is your marital status?</p> <p><input type="checkbox"/> Single</p> <p><input type="checkbox"/> Married</p> <p><input type="checkbox"/> Living with a partner</p> <p><input type="checkbox"/> Divorced</p> <p><input type="checkbox"/> Separated</p> <p><input type="checkbox"/> Widowed</p>
<p>6. Are you or your partner currently pregnant?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>7. Have you or your partner ever been pregnant?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>8. How many children do you have? _____</p>
<p>9. When you complete your education, what type of community do you intend to practice in? Check all that apply.</p> <p>For the purposes of this question, an urban community would include Sudbury, Timmins, and Sault Ste. Marie; a rural community would include</p>

Kapuskasing and Elliot Lake; a remote community would include Sioux Lookout, Moose Factory, and Attawapiskat. A Northern community would include any location north of Parry Sound.

Rural Urban Sub-urban Remote Northern Southern
 First Nations community other (please specify): _____

10. What is the anticipated date of completion for your program? (please indicate year) _____

11. Do you have a family member or close friend with a developmental disability?

Yes No

If yes, what developmental disability?

12. Which degrees and/or qualifications have you already completed?	<i>Degree/Qualification</i>	<i>Educational Institution, City</i>	<i>Year of Completion</i>

We would like to ask you some questions on your knowledge about developmental disabilities.

13. How would you rate your current level of knowledge regarding the <u>assessment/diagnosis</u> of individuals with the following:	<i>Very limited</i>	<i>Limited</i>	<i>Moderate</i>	<i>Extensive</i>
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other disability (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. How would you rate your current level of knowledge regarding the treatment of individuals with the following:	<i>Very limited</i>	<i>Limited</i>	<i>Moderate</i>	<i>Extensive</i>
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other disability (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Have you participated in any training sessions or workshops on any of the following topics:	<i>General undergraduate training (e.g., BA, BSc, etc.)</i>	<i>Professional /graduate training (e.g., MD, BScN, MSc, MSW, PhD, etc.)</i>	<i>Other training (please specify)</i>
Assessment/diagnosis of individuals with developmental disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Treatment of individuals with developmental disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____

Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____
Other disability (please specify):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> _____

16. Overall, how helpful did you find the following for increasing your knowledge about developmental disabilities?	<i>Not helpful</i>	<i>Moderately helpful</i>	<i>Very helpful</i>
General undergraduate training (e.g., BA, BSc, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professional/postgraduate training (e.g., MD, BScN, MSc, MSW, PhD, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify): _____ _____ _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17a. Do you have experience (work or volunteer) with individuals with the following disabilities? (choose all that apply)	<i>None</i>	<i>Very Limited</i>	<i>Limited</i>	<i>Moderate</i>	<i>Extensive</i>
Autism spectrum disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fetal alcohol spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disabilities (e.g., cerebral palsy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hearing and/or visual difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other disability (please specify):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>17b. Do you feel that you had enough access to information or resources (at school or online) to meet the needs of these individuals? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>17c. If not, what resources would be most helpful? Check all that apply. <input type="checkbox"/> Web-based material <input type="checkbox"/> Written material (books, journal articles, etc.) <input type="checkbox"/> Information obtained from workshops/training seminars <input type="checkbox"/> Webinars <input type="checkbox"/> Information obtained from colleagues <input type="checkbox"/> Other (please specify) _____</p>					
<p>18. In what areas would you like more training or education about different developmental disabilities? Check all that apply. <input type="checkbox"/> Social Skills <input type="checkbox"/> Language Skills <input type="checkbox"/> Fine/Gross Motor Skills <input type="checkbox"/> Memory <input type="checkbox"/> Sensory <input type="checkbox"/> Other (please specify) _____</p>					
<p>19. If you had questions regarding an individual with a developmental disability, whom would you most likely go to for help? <input type="checkbox"/> Child Care Workers <input type="checkbox"/> Psychologists <input type="checkbox"/> Special Needs Consultants <input type="checkbox"/> Speech and Language Pathologists <input type="checkbox"/> Social Workers <input type="checkbox"/> Other (please specify): _____</p>					
	<i>Not very competent</i>	<i>Mildly competent</i>	<i>Moderately competent</i>	<i>Very competent</i>	
20. How competent do you feel <u>collaborating</u> with different healthcare providers, educators, and other professionals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<i>Not very</i>	<i>Mildly</i>	<i>Moderately</i>	<i>Very</i>	

	<i>competent</i> <i>(could meet few needs)</i>	<i>competent</i> <i>(could meet some needs)</i>	<i>competent</i> <i>(could meet most needs)</i>	<i>competent</i> <i>(could meet all needs expertly)</i>
21. How competent do you feel in <u>meeting the needs</u> of individuals with developmental disabilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22a. Have you had experience (in class or on placement) working as part of an inter-professional team? <input type="checkbox"/> No <input type="checkbox"/> Yes				
22b. If yes, was this experience in the field of developmental disabilities? <input type="checkbox"/> Yes <input type="checkbox"/> No (please specify), it was in the field of _____				
23a. Do you belong to any organizations or groups supporting individuals with developmental disabilities? <input type="checkbox"/> No <input type="checkbox"/> Yes				
23b. If yes, what organizations? (please specify):				

APPENDIX D – Fetal Alcohol Spectrum Disorder Survey for Health Care Students

Fetal Alcohol Spectrum Disorder Survey for Health Care Students

Part A (General knowledge and attitudes)

In recent years there has been increased investigation about the effects of alcohol consumption during pregnancy and the potential for subsequent morbidity and mortality among offspring. Experimental findings have been the main focus. Clinical aspects have received less attention. It would be helpful to know what information has reached you, whether it has been useful, and how it could be improved. This questionnaire will take approximately 15 minutes to complete.

Fetal Alcohol Spectrum Disorder:

What is your definition of Fetal Alcohol Spectrum Disorder (FASD)?

1. When did you first hear of FASD? (Please select one answer only.)

- In the last year or two
- Three to four years ago
- More than four years ago
- Never

2. From what sources have you gained knowledge about FASD? (Please select all that apply).

- Mass Media
- Parents/patients
- Colleagues
- CME seminars, rounds
- Webinar
- Medical journals, books
- Medical school, residency, fellowship
- Nurse practitioner training
- Midwifery program training
- Other (please specify):

3. In your opinion, is the incidence of FASD in Canada higher, equivalent, or lower than the incidence of each of the following?				
	<i>Higher</i>	<i>Equivalent</i>	<i>Lower</i>	<i>Don't Know</i>
Down Syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spina Bifida	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cerebral Palsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Autism Spectrum Disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fragile X Syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Please indicate your opinion on the following statements:					
	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>	<i>Undecided</i>
Alcohol's effects on fetal development remains unclear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is the physician's role to manage problems in the area of alcohol use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is the midwife's role to manage problems in the area of alcohol use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is the nurse practitioner's role to manage problems in the area of alcohol use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FASD occurs at similar rates among all cultures and ethnic groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The drinking patterns of pregnant women are substantially influenced by the drinking patterns of their male partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discussing alcohol use during pregnancy will frighten or anger patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discussing the use of alcohol during pregnancy will deter women from continuing and/or seeking treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Making a diagnosis of FASD does not change anything for the child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prenatal alcohol exposure is a significant risk factor for permanent brain damage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Alcohol Use:

5. Patients, both men and women, are often told to drink only “in moderation.”					
What is your definition of a moderate level of alcohol consumption for <u>non-pregnant women</u>?					

Average number of drinks per occasion: _____					
Average number of drinking occasions per week: _____					
On average, how many drinks per week do you consume? _____					
On average, how many drinks per occasion do you consume? _____					
6. How prepared do you feel to care for the following groups of clients in the area of alcohol abuse or dependency?					
	<i>Very prepared</i>	<i>Prepared</i>	<i>Unprepared</i>	<i>Very unprepared</i>	<i>Will not care for</i>
Pregnant women	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Birth mothers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Foster parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adoptive parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individuals with FASD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How prepared do you feel to access resources for the following groups of clients in the area of alcohol abuse or dependency?					
	<i>Very prepared</i>	<i>Prepared</i>	<i>Unprepared</i>	<i>Very unprepared</i>	<i>Will not care for</i>
Pregnant women	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Birth mothers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Foster parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adoptive parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individuals with FASD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part B
(Prevention issues)

Women receive different types of information about how to achieve and maintain a healthy pregnancy. Please consider your own training when answering the following questions.

Non-Pregnant Women:

8. Do you anticipate treating non-pregnant women of childbearing age? Yes <input type="checkbox"/> No <input type="checkbox"/>				
9. Based on your training, how often would you anticipate discussing the following with <i>all women of childbearing age</i>?				
	<i>Frequently</i>	<i>Sometimes</i>	<i>Rarely</i>	<i>Never</i>
Role of folic acid in decreasing neural tube defects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risks of smoking during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risks of alcohol during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner's use of drugs and alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Birth control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Based on your training, how often would you anticipate routinely <i>obtaining a detailed history</i> about the following from <i>all women of childbearing age</i>?				
	<i>Frequently</i>	<i>Sometimes</i>	<i>Rarely</i>	<i>Never</i>
Sexual abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal history of addictions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family history of alcohol misuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. There are many reasons why health care professionals may not talk to women about alcohol use before they become pregnant. Please indicate whether you believe any of following are reasons that health care professionals may not talk to women about alcohol use:				
	<i>Yes</i>	<i>No</i>		
There is not enough time in an office visit to talk to women about these topics	<input type="checkbox"/>	<input type="checkbox"/>		
There is not enough solid information available about alcohol use	<input type="checkbox"/>	<input type="checkbox"/>		
Many clients are not interested in discussing alcohol use	<input type="checkbox"/>	<input type="checkbox"/>		
Many clients already have a good knowledge about alcohol use	<input type="checkbox"/>	<input type="checkbox"/>		
Information about alcohol use is not available in a	<input type="checkbox"/>	<input type="checkbox"/>		

form that may be useful to clients		
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Pregnant Women:

12. Would you consider the following to be <i>barriers to women seeking care for alcohol use during pregnancy</i>?		
	<i>Yes</i>	<i>No</i>
Dual diagnoses (e.g., depression, bipolar disorder, panic attacks)	<input type="checkbox"/>	<input type="checkbox"/>
History of sexual abuse or domestic abuse	<input type="checkbox"/>	<input type="checkbox"/>
Co-dependence (partner/peer/parental substance abuse)	<input type="checkbox"/>	<input type="checkbox"/>
Current violence in the home	<input type="checkbox"/>	<input type="checkbox"/>
Extrinsic barriers (e.g., childcare, housing, transportation, poverty)	<input type="checkbox"/>	<input type="checkbox"/>
Fear of public shame, blame, etc.	<input type="checkbox"/>	<input type="checkbox"/>
Misinformation about the safety of alcohol use during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>
Fear of losing children to partner or child welfare	<input type="checkbox"/>	<input type="checkbox"/>
System prejudice based on social/economic class	<input type="checkbox"/>	<input type="checkbox"/>
Communication/language barriers	<input type="checkbox"/>	<input type="checkbox"/>
Absence of addiction treatment services	<input type="checkbox"/>	<input type="checkbox"/>
Absence of gender-specific addiction treatment services	<input type="checkbox"/>	<input type="checkbox"/>
13. Please indicate if you are familiar with, and would feel competent using, any of the alcohol screening tools or tests listed below. (Please check all that apply.) <input type="checkbox"/> None <input type="checkbox"/> T-ACE (Tolerance, Annoyed, Cut Down, Eye-Opener) <input type="checkbox"/> TWEAK (Tolerance, Worried, Eye-Opener, Amnesia, K/Cut Down) <input type="checkbox"/> CAGE (Cut Down, Annoyed, Guilty, Eye-Opener) <input type="checkbox"/> MAST (Michigan Alcoholism Screening Test) <input type="checkbox"/> AUDIT (Alcohol Use Disorders Identification Test) <input type="checkbox"/> Urine or blood test <input type="checkbox"/> Other (please specify): _____		
14. Which of the following best describes the advice you would give pregnant women regarding alcohol use during pregnancy? <input type="checkbox"/> No alcohol is recommended <input type="checkbox"/> Alcohol is only dangerous during the first trimester <input type="checkbox"/> A glass of beer or wine in moderation is OK <input type="checkbox"/> No specific recommendations would be given <input type="checkbox"/> Other (please specify): _____		

Part C
(Diagnostic issues)

15. Do you think there should be a mandatory reporting of FASD? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know			
16. Is FASD a reportable condition in the province of Ontario? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know			
17. In your opinion, do the following characteristics define Fetal Alcohol Spectrum Disorder?			
	<i>Yes</i>	<i>No</i>	<i>Don't know</i>
Prominent forehead	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Flat philtrum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thin upper lip	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thick upper lip	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short palpebral fissures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upslanting palpebral fissures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Downslanting palpebral fissures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Central nervous system dysfunction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prenatal growth deficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Postnatal growth deficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Which of the following items would give you the most accurate information regarding the diagnosis of Fetal Alcohol Spectrum Disorder? (Please select <i>one</i> only.) <input type="checkbox"/> Mother has history of alcohol abuse or dependency <input type="checkbox"/> Small at birth <input type="checkbox"/> Behaviour problems <input type="checkbox"/> Cognitive problems <input type="checkbox"/> Special facial characteristics <input type="checkbox"/> Combination of growth, brain, and facial abnormalities			

19. Please indicate whether the following, in your opinion, are associated with or are directly caused by FASD:				
	<i>Associated with FASD</i>	<i>Directly caused by FASD</i>	<i>Neither</i>	<i>Don't know</i>
Long term emotional disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disrupted school experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Addictions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Cleft palate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attention deficit disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low IQ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Average IQ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High IQ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inappropriate sexual behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypersensitivity to stimuli	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behaviour problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aggressive behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor self esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with social interactions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dependent living arrangements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>20. Many doctors do not make a diagnosis of FASD in their practice. Please indicate which of the following factors may contribute to this situation. (Please select <i>all</i> that apply).</p> <p>If making the diagnosis would be beyond your scope of practice, please check this box. <input type="checkbox"/></p> <p><input type="checkbox"/> Lack of time needed to make diagnosis</p> <p><input type="checkbox"/> Lack of specific training to make the diagnosis</p> <p><input type="checkbox"/> Lack of access to FASD specialists</p> <p><input type="checkbox"/> Belief that making the diagnosis will not make a difference to the individual</p> <p><input type="checkbox"/> Belief that making the diagnosis will lead to stigmatization of the individual and the family</p> <p><input type="checkbox"/> Other (please specify): _____</p>				
<p>21. Are you aware of/familiar with any FASD guidelines for diagnosis?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If so, can you name and briefly describe them?</p> <p>_____</p> <p>_____</p> <p>_____</p>				

APPENDIX E – Semi-Structured Interview Guide for Health Care Students

Semi-Structured Interview Guide for Health Care Students

1. Tell me about your health care education program that you are currently enrolled in (i.e., medical school, nursing program, midwifery program).
2. What led you to want to train in Northern Ontario?
 - *Follow-up:* According to you, when is a community considered a rural community? A Northern community?
3. Have you ever heard of fetal alcohol spectrum disorder (FASD)? What do you know about FASD?
4. Where do you obtain your information about FASD? How do these sources impact your perception of FASD?
 - *Follow-up:* What is your perception regarding how FASD is currently portrayed and discussed in the media? Greater society?
 - *Follow-up:* Have you been exposed to FASD during your education? How? In what context did you receive this education or training? *Prompt:* Did you learn about FASD in relation to developmental disabilities? Women's health? Prenatal care? Etc.
5. What previous experience, if any, do you have with people with intellectual or developmental disabilities? FASD?
 - *Follow-up:* How do you feel about working with people with intellectual or developmental disabilities? FASD?
6. How have these previous experiences influenced your perceived self-efficacy (*ability*) to care for individuals with intellectual or developmental disabilities? FASD? Their families?
 - Could you give an example of a situation in which you felt particularly successful in meeting the needs of an individual with an intellectual or developmental disability?
 - Could you give an example of a situation in which you felt that you faced challenges in meeting the needs of an individual with an intellectual or developmental disability?
 - *Follow-up:* If you do not feel prepared, what would help you to feel prepared to work with individuals with intellectual or developmental disabilities? FASD? Their families?
 - *Follow-up:* How do you feel about interprofessional learning and training? How would this type of education help (or not help) you in learning about intellectual and developmental disabilities? FASD?
7. What would you tell a woman who was pregnant about alcohol consumption during pregnancy? What would you tell a woman who was of childbearing age, or planning to become pregnant, about alcohol consumption during pregnancy?
 - *Follow-up:* What do you know about Canadian guidelines to address or manage FASD? Can you briefly name and describe them?
 - *Follow-up:* What do you know about Canada's Low Risk Drinking Guidelines?
8. How do you think your program of study/training is set up to take care of individuals with intellectual or developmental disabilities? FASD?
9. What do you consider to be required to care for individuals with FASD? What community and health care services do you think must be accessed?
 - *Prompt:* How do you think rural and northern health care issues impact care for people with FASD (or with intellectual or developmental disabilities in general)?
10. If you were helping to design a curriculum on fetal alcohol spectrum disorder, what would you include?

APPENDIX F – Vignettes

Vignette #1

Shannon is a 32-year-old, married woman who is pregnant with her first child. Shannon has a bachelor's degree in Labour Studies and Communications from an Ontario university and works as a marketing consultant at a top marketing firm in Toronto, Ontario. Shannon has a very active social life, and has a weekly dinner date after work with five of her closest female friends.

Shannon is currently seven months pregnant. While Shannon did not drink at all during her first trimester, she drank occasionally and lightly throughout her second and third trimesters. Shannon has never binged drank or gotten drunk, and has never had any hard liquor during her pregnancy. She says that she often has a glass or two of wine or a couple beers per week. Shannon's friends frequently reassure her that having a few drinks during her pregnancy does not pose any risk to her baby.

While Shannon claims that she could go the nine months without drinking any alcohol, she believes there is no conclusive evidence that light drinking during pregnancy will harm her baby. Shannon feels as though keeping as much of her normal, non-pregnant life as possible is benefiting her physically and mentally, including consuming a few drinks with her friends at dinner or when celebrating important events.

Questions:

- What are your first impressions of this vignette?
- As a health care professional, what advice would you give to Shannon at this stage of her pregnancy (third trimester)? What advice would you have given to Shannon at the beginning of her pregnancy?
- Do you think what Shannon is doing during her pregnancy poses any risks to her unborn child? Why or why not?
- How comfortable do you feel addressing this situation?

Vignette #2

Kimberly is a 23-year-old, unmarried woman who is pregnant for the first time. Kimberly lives in a small, rural community in northern Ontario that is two hours from the closest urban center. Kimberly owns her own car, but commuting is often problematic due to her erratic work hours and weather in the wintertime.

Kimberly is currently five months pregnant. Kimberly found out she was pregnant at eight weeks. Even though Kimberly rarely drinks, she stopped drinking completely upon finding out she was pregnant. However, Kimberly attended a friend's birthday party before she discovered she was pregnant and recalls drinking about ten drinks on that occasion, during her third week of pregnancy.

Kimberly has a strong social support network around her, particularly from her friends and her mother who still lives in the same community. However, Kimberly's partner and the father of her child continues to drink in front of her, even though Kimberly has requested that he not drink. In certain social situations, her partner has urged her to have a couple drinks to help her relax and have fun. In these instances, Kimberly has chosen to drink a non-alcoholic cocktail or a non-alcoholic glass of wine instead of an alcoholic beverage.

Questions:

- What are your first impressions of this vignette?
- As a health care professional, what advice would you give to Kimberly at this stage of her pregnancy (second trimester)? What advice would you have given to Kimberly before she became pregnant?
- Do you think what Kimberly did at the beginning of her pregnancy poses any risks to her unborn child? Why or why not?
- How comfortable do you feel addressing this situation?

Vignette #3

Jessica is a 30-year-old, married woman who is pregnant for the first time. Jessica obtained a Bachelor of Arts degree in English and a Bachelor of Education from a southern Ontario university. While Jessica has lived in a major urban center for several years, she has recently moved back to her home community in a small, rural town in southern Ontario to accept a teaching position.

Jessica is currently three months pregnant. When Jessica made an appointment to see her family doctor, she expressed some concern and anxiety about her pregnancy. Because this is Jessica's first pregnancy, she is worried and uncertain about what to expect. Her doctor reassured her that everything was fine and that if she was really worried she should have a few drinks to help her relax and to get a better sleep. Although Jessica never drinks alcohol, she accepted the doctor's advice.

Questions:

- What are your first impressions of this vignette?
- As a health care professional, what advice would you give to Jessica at this stage of her pregnancy (first trimester)? What advice would you have given to Jessica before she became pregnant?
- Do you think the advice the family doctor gave Jessica poses any risks to her unborn child? Why or why not?
- How comfortable do you feel addressing this situation?

Vignette #4

Samantha is a 19-year-old, unmarried woman who is pregnant. Samantha lives in an urban city in Northern Ontario. Samantha's pregnancy was unplanned, and she is not currently in a committed relationship. Samantha has a high school education and currently works part-time as a cook at a local restaurant.

Samantha is currently four months pregnant. This pregnancy is Samantha's second pregnancy, but this would be her first child. Samantha was diagnosed with Fetal Alcohol Spectrum Disorder (FASD) when she was 11 years old. She currently lives with her adoptive parents, who are supportive of this pregnancy and who have agreed to help raise her child.

Although Samantha is currently doing well, her parents have concerns about Samantha's potential secondary adverse outcomes. Samantha's parents are worried that she may drink during her pregnancy and suspect that Samantha may have been drinking prior to realizing that she was pregnant. Samantha is adamant that she has not been drinking and that she is determined to stay sober throughout her pregnancy.

- What are your first impressions of this vignette?
- As a health care professional, what advice would you give Samantha at this stage of her pregnancy (second trimester)? What advice would you have given to Samantha before she became pregnant?
- Do you think Samantha's FASD poses any risk to her pregnancy?
- How comfortable do you feel addressing this situation?

APPENDIX G – Ethics Approval



Laurentian University
Université Laurentienne

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
 Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension	
Name of Principal Investigator and school/department	Celisse Bibr, Kelly Coons, School of Rural & Northern Health, supervisor Shelley Watson
Title of Project	The Knowledge and Advice of Northern Ontario School of Medicine Students on the Subject of Fetal Alcohol Spectrum Disorder
REB file number	6009963
Date of original approval of project	June 22, 2017
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on: <i>(You may request an extension)</i>	June 22, 2018
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*

APPENDIX H – Phase I Consent Form

(online consent form)

As a health care professional in training, you are invited to participate in this study.

Who are we? We are a team of researchers and students at Laurentian University who are interested in studying Fetal Alcohol Spectrum Disorder (FASD) and developmental disabilities. We come from several departments, including the School of Rural and Northern Health and the Department of Psychology. This study specifically is conducted by a MA candidate, Celisse Bibr, in the School of Rural and Northern Health, to fulfill the requirements for a MA degree.

Why are we working together? We want to study:

1. What Northern Ontario health care students know and believe about FASD and developmental disabilities in general
2. How Northern Ontario health care students feel about FASD and alcohol consumption during pregnancy
3. Where, and what, Northern Ontario health care students learn about FASD
4. How prepared and confident Northern Ontario health care students feel about working with individuals with FASD, their families, and pregnant women

What is this project about? This research project will examine medical students at the Northern Ontario School of Medicine. This research will identify what different health care professional groups know about FASD and will explore how prepared each group feels to work with individuals with FASD, their families, and pregnant women.

What will we ask you to do? We will ask you to answer online questions about your knowledge and experiences regarding individuals with developmental disabilities and FASD. In addition, we will ask you about your experiences and beliefs about interprofessional learning. You do not have to answer all questions if you do not want to. Also, you can discontinue your participation at any time without penalty.

How long will it take? The questionnaires will take approximately 20-30 minutes to complete.

Are there benefits to you if you agree to participate? The information we gather will be used to identify areas within health care curricula that may need additional attention. The information we gather will also be used to improve the confidence, self-efficacy, perceived competency, and knowledge of future health care professionals regarding developmental disabilities and FASD.

How will your information be used? All information we collect will be private and kept confidential. No one will see the answers you give to questions except members of the research team. All information will be stored in a locked filing cabinet or in a password protected file. Your personal information, such as your name, e-mail address, and phone number, will kept separate from your questionnaire responses. All data will be destroyed 5 years after the study's completion.

Are there any possible risks for harm? There is minimal or low risk associated with this study. If you experience negative or distressing emotions if a particularly stressful experience or topic is discussed, you are welcome to take a break, choose not to answer a question, or withdraw from the study without penalty.

For more information about this study, please contact: Celisse Bibr, M.A. Candidate, Principal Investigator, School of Rural and Northern Health, Laurentian University, at cbibr@laurentian.ca

If I have any questions or concerns about this project, I may contact:

Celisse Bibr, M.A. Candidate, at cbibr@laurentian.ca at any time, or Dr. Shelley Watson, PhD, at 705-675-1151 or 1-800-461-4030, extension 4223, or swatson@laurentian.ca
If my questions or concerns are not answered, I may contact the Research Ethics Officer, Laurentian University, at 705-675-1151 or 1-800-461-4030, extension 3213, or at ethics@laurentian.ca

My questions about this project have been answered and I understand that:

- I do not have to answer all of the questions
- My answers will be anonymous
- All information will be kept confidential and secure
- There are no particular risks if I participate
- I may withdraw from the study at any time without penalty
- I may keep this information about the study

I understand that by completing this questionnaire, I am agreeing to participate in this study.

Would you also be interested in participating in a semi-structured interview about your experiences as a health care student in relation to developmental disabilities and fetal alcohol spectrum disorder? You will receive a \$5 Amazon gift card for your participation in this interview. If yes, please indicate below and provide your contact information.

No Yes

Name: _____

E-mail Address: _____

Phone Number: _____



APPENDIX I – Phase II Consent Form
(on University Letterhead)

I agree to participate in the research project entitled “the Knowledge and Advice of Northern Ontario School of Medicine (NOSM) Students on the Subject of Fetal Alcohol Spectrum Disorder (FASD)”. I understand that I will receive a \$5 Amazon gift card for my participation.

I understand that the goals of this research are to understand what different health care students know and believe about FASD. By investigating the knowledge and advice held by health care students, there is potential to identify areas where students may need increased education regarding FASD or other developmental disabilities, allowing for changes to health care curricula. There are also potential benefits to participants, as this study may improve their confidence, self-efficacy, perceived competency and knowledge regarding FASD. With the inclusion of scenario-based vignettes, there is potential for knowledge mobilization to occur immediately, as the vignettes may be used as a case-based teaching tool within the health care curricula.

I understand that I will be asked to participate in an interview and answer questions regarding a vignette scenario. This interview will last approximately 45 minutes to one hour, with the chance of follow-up questions. I will be asked questions about my program of study, my perceptions and beliefs about alcohol consumption during pregnancy, some of my personal and professional experiences, my awareness of FASD, and health care needs in rural and Northern Ontario. I understand that the interview will be audio recorded, and that I can opt out of being audio recorded without penalty.

I understand that I do not have to participate in this study. **I may stop participating at any time without penalty.** I acknowledge that by participating in the research I may be exposed to minor risks. I understand that the interview may bring up topics that I may not be knowledgeable about or that I may be uncomfortable discussing. I can choose not to answer any questions or take a break at any time without penalty. If I feel uncomfortable, I can take a break or stop the interview at any time without penalty.

I understand that all information collected will be used for research purposes only. I understand that my anonymity will be protected. Any personal information collected during the study will stay private and confidential. I understand that any identifying information about me, such as my name, will be changed to ensure confidentiality. I understand that all interview transcripts, audio recordings, and questionnaire data will be destroyed 5 years after the end of this project. I also understand that I will have a chance to look at my interview transcript to make sure it accurately shows what I have said during the interview. By reviewing my interview transcript, I will have an opportunity to inform the researcher of any information I gave that I might be uncomfortable with having shared or may provide further clarification information on what I have said. I also understand that I may be contacted again to clarify my responses or answer any follow up questions. If I want, I may receive a summary of the results at the end of the study (please check below). I understand that all raw data will be destroyed 5 years after the study’s completion.

If I have any questions regarding the purpose or nature of the study, I can contact Celisse Bibr by e-mail at cbibr@laurentian.ca, or her supervisor, Shelley Watson, Ph.D., by phone at 705-675-1151 or 1-800-461-4030, extension 4223, or by e-mail at swatson@laurentian.ca. If I have concerns regarding the ethics of the study, I may contact the Research Ethics Officer, Laurentian University Research Office, by phone at 705-675-1151 or 1-800-461-4030, extension 3213, or by e-mail at ethics@laurentian.ca

After reviewing this consent form, I agree to participate in this research project.

PARTICIPANT: _____

(Signature)

DATE:

Name:

Daytime phone number:

E-mail address:

I would like to receive a copy of the results at the end of this study. Yes No



APPENDIX J – Community Resources

- **Public Health Ontario**
480 University Avenue, Suite 300
Toronto, ON M5G 1V2
Tel: 647-260-7100
Toll Free: 1-877-543-8931
E-mail: communications@oahpp.ca
- **Sudbury and District Health Unit**
1300 Paris Street
Sudbury, ON P3E 3A3
Tel: 705-522-9200
Toll Free: 1-866-522-9200
- **Thunder Bay District Health Unit**
999 Balmoral Street
Thunder Bay, ON P7B 6E7
Tel: 807-625-5900
Toll Free: 1-888-294-6630
- **Canadian Mental Health Association (CAMH) Sudbury/Manitoulin Branch**
111 Elm Street, Suite 100
Sudbury, ON P3C 1T3
Tel: 705-675-7252
Toll Free: 1-866-285-2642
E-mail: info@cmha-sm.ca
- **Canadian Mental Health Association (CAMH) Thunder Bay Branch**
200 Van Norman Street
Thunder Bay, ON P7A 4B8
Tel: 807-345-5564
E-mail: cmhatb@cmha-tb.on.ca
- **Centre for Addiction and Mental Health**
1001 Queen Street West
Toronto, ON M6J 1H4
Tel: 416-535-8501
Toll Free: 1-800-463-2338
- **Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASD ONE)**
860 Richmond Street West, Suite 100
Toronto, ON M6J 1C9
E-mail: info@fasdontario.ca