

Are Rural and Urban Ontario Health Care Professionals Aware of Fetal Alcohol Spectrum Disorder? A Secondary Data Analysis of the Fetal Alcohol Syndrome Survey for Health Professionals

Abstract

Health care professionals play a critical role in the prevention of FASD, particularly through providing counselling around alcohol use and alcohol consumption during pregnancy, yet researchers have demonstrated that many professionals remain under-educated concerning FASD. In addition, awareness of FASD held by Ontario health care professionals remains unexplored. A secondary data analysis was conducted using data obtained from the 2001-2002 Fetal Alcohol Syndrome (FAS) Survey for Health Professionals. Ontario-specific data (N = 834) were used to examine the awareness of FASD held by various health care professionals in both rural and urban settings. Nearly all (99.5%) of the surveyed health care professionals had previously heard of FASD; however, only 73.2% reported discussing the risks of alcohol during pregnancy, 62.4% agreed with the practice of telling patients to drink in moderation, and only 87.9% recommended that pregnant women completely abstain from alcohol for the duration of their pregnancy. Using Chi-squared comparisons, results also showed that rural providers were more likely than urban providers to ask pregnant women if they are currently drinking alcohol ($p = .007$) and felt more prepared to care for biological mothers in the area of alcohol use or dependency ($p = .011$). Health care professionals' counselling and recommendations for pregnant women about alcohol use, as well as FASD prevention, are discussed.

Fetal alcohol spectrum disorder (FASD) is an umbrella term that refers to a continuum of effects associated with prenatal exposure to alcohol. Prior to the introduction of new Canadian guidelines for the diagnosis of FASD (Cook et al., 2015), the term was used to describe a range of conditions on the spectrum including fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), partial FAS (p-FAS), and alcohol related neurodevelopmental disorder (ARND; Streissguth et al., 2004). These terms are now antiquated given the new updated guidelines; however, the terms FAS and FAE are used throughout this paper as this was the terminology employed in the original questionnaire, prior to the development of clear diagnostic guidelines.

Estimates for the prevalence of FASDs are relatively undetermined due to challenges with the diagnostic process. A number of "diagnostic dilemmas" influence reported FASD prevalence rates, including challenges with changing diagnostic criteria and changing facial characteristics (e.g., less

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pronounced facial characteristics over time), inconsistencies in the level of understanding of the disability, as well as the perceived stigmatization of the label of FASD for both families and children (Chandrasena, Mukherjee, & Turk, 2009). However, researchers who have estimated the prevalence of FASD have reported an approximate rate of 1 to 6 per 1,000 live births in the general population (Stade, Stevens, Ungar, Beyene, & Koren, 2006), with some estimates as high as 9.1 per 1,000 live births in both Canada and the United States (Alberta Alcohol and Drug Abuse Commission, 2004; Chudley et al., 2005). A recent study examining the prevalence and characteristics of FASD among first grade students in a representative Midwestern United States community found that as many as 1 in 20 children may have an FASD, indicating that FASDs may be much more prevalent than previously predicted (May et al., 2014).

Researchers have demonstrated that parents frequently perceive health care professionals and service providers to be unaware of the signs and symptoms associated with FASD (Brown & Bednar, 2004; Caley, Winkelman, & Mariano, 2009; Salmon, 2008) and consequently parents often feel unsupported by medical and health care professionals (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013; Ryan, Bonnett, & Gass, 2006; Salmon, 2008; Sanders & Buck, 2010; Watson, Hayes, Coons, & Radford-Paz, 2013). Current research involving families of children with FASD in Ontario reveals that while a minority of families reported that accessing formal support from professionals such as psychiatrists, paediatricians, and family physicians, was helpful, the majority of families felt that doctors lacked knowledge of FASD and were therefore not effective (Coons, Watson, Schinke, & Yantzi, 2016). Despite a relatively large body of literature examining knowledge, attitudes, and awareness of FASD in Canada in general, the United States, and Australia, limited research has examined the level of awareness of FASD held by Ontario health care professionals.

Lack of Knowledge, Awareness, and Understanding of FASD

Health care professionals play a critical role in the prevention of FASD, particularly through guidance regarding alcohol consumption dur-

ing pregnancy. National survey results suggest that Canadian health care providers require further training and education regarding both individuals at risk for having a child with FASD and for individuals with FASD, as well as their families (Clarke, Tough, Hicks, & Clarren, 2005; Tough, Clarke, Hicks, & Clarren, 2005a, 2005b). In particular, findings indicate that health care professionals need assistance in making valid diagnoses and referrals (Clarke et al., 2005; Public Health Agency of Canada [PHAC], 2005a). Only 60% of health care providers surveyed in two studies accurately recognized the most correct information concerning a diagnosis of Fetal Alcohol Syndrome (FAS) according to the diagnostic systems in place at the time (e.g., a combination of growth, brain, and facial abnormalities; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Clarke et al., 2005).

In addition to Canadian findings, international studies in the United States and Australia have identified similar deficits in health care professionals' knowledge of FASD (e.g., Anderson et al., 2010; Elliott, Payne, Morris, Haan, & Bower, 2008; Payne et al., 2005; Payne et al., 2011a; Payne et al., 2011b; Payne et al., 2014). For example, a study of 1143 Western Australian health professionals identified that only 67% of general practitioners routinely ask about alcohol use during pregnancy, with 24% indicating that they "sometimes" ask (Payne et al., 2005). Payne et al. (2011b) conducted a follow up study of paediatricians in Western Australia and found that only 27.1% of their sample routinely asked about alcohol use when taking a pregnancy history and few physicians (10.1%) routinely provided information to their patients about the consequences of alcohol use during pregnancy. Few general practitioners said they routinely gave information regarding the consequences of alcohol on the fetus and 17% said they did not provide this information at all to their patients (Payne et al., 2005).

Elliott et al. (2008) also found that 23.3% of paediatricians in Australia did not routinely ask about alcohol use when taking a pregnancy history. Unfortunately, Payne et al.'s (2011b) study also found that few paediatricians reported feeling very prepared to deal with FAS (e.g., ~6%) and more than two thirds (67.1%) believed that giving a formal diagnosis of FAS was stigmatizing to the individual with FASD and their family. Findings from Anderson et al. (2010) also demonstrate breakdowns in the continuity of care

for individuals with FASD. Specifically, less than half of obstetricians and gynaecologists in their United States study responded that they always communicate information about alcohol use during pregnancy to the newborn's paediatrician.

Compared to all other professional groups, midwives demonstrate significantly better knowledge of FASD and pregnancy counselling. For example, in a Western Australian study, Payne et al. (2014) found that 93.2% of midwives asked pregnant women about their alcohol consumption and 99.4% provided pregnant women with advice about alcohol consumption during pregnancy (e.g., not drinking in pregnancy is the safest option). However, almost half of midwives thought that asking every pregnant woman about their alcohol consumption during pregnancy could distress or anger their patient, could cause anxiety and guilt, could lead to feelings of judgment, and could uncover complex problems that are difficult for midwives to address. Additionally, 32.1% of midwives believed that infrequent consumption of a standard drink of alcohol during pregnancy is not harmful to the fetus or the mother (Payne et al., 2014). Similar results have also been demonstrated with other professional populations, such as family physicians, general practitioners, and obstetricians or gynaecologists, who indicate that one or more drinks per week or per occasion are likely safe for a pregnant woman (e.g., Anderson et al., 2010). These findings indicate that while different provider groups all have some level of knowledge regarding FASD, misconceptions and stereotypes also exist.

Rural and urban differences may also be relevant because suggested prevalence rates of FAS have been found to be highest in rural and remote communities (Tough, Ediger, Hicks, & Clarke, 2008; Viljoen, Croxford, Gossage, Kodituwakku, & May, 2002). Tough and colleagues (2008) examined differences between rural and urban health care providers in Canada with regards to their knowledge of, attitudes about, and awareness of FASD and preconception counselling practices. Despite few differences between rural and urban care providers' general knowledge and diagnostic knowledge of FASD, rural providers were in fact more prepared to access resources for women with addiction issues and were more likely to care for patients with an FASD (Tough et al., 2008). Tough et al. (2008) also found that rural providers were significantly more likely

to report caring for patients with FAS and to have referred a patient for diagnosis. Despite this demonstrated knowledge of FASD among rural and remote communities across Canada, the level of knowledge of FASD within Ontario remains unclear.

Because families of children with FASD in Ontario frequently report feeling under-supported by those from whom they expect help (Coons et al., 2016), it is essential to understand what these various professionals know about FASD. While researchers have addressed the level of knowledge of FASD held by health care professionals in Australia, the United States, and Canada as a whole, to the authors' knowledge, no study has examined the level of knowledge held by Ontario health care providers. It is especially relevant to focus on under-researched populations, such as midwives, and those from regions of extremely underestimated numbers of FASDs, such as Northern Ontario.

A secondary analysis of the Ontario-specific data collected as part of the 2001–2002 Fetal Alcohol Syndrome (FAS) Survey for Health Professionals will provide insight into the awareness and comprehension of FASD held by Ontario health care professionals in the early 2000s. Though the data are 15 years old, creating limitations in the understanding of health care professionals' current level of knowledge and awareness concerning FASD, the analysis of this information is timely and relevant as it provides an insight into the historical attitudes and knowledge of health care providers prior to established diagnostic guidelines. By examining historical knowledge, we are better able to understand whether or not updated guidelines and training conducted over the past decade have been effective in increasing awareness of FASD, and in understanding the context of service delivery in Ontario. This analysis will assist in determining the previous level of knowledge surrounding FASD, as well as health care providers' common practices and recommendations, held prior to the release of national guidelines addressing FASD, which were first established in 2005 (Chudley et al., 2005) and recently updated in 2015 (Cook et al., 2015). By better understanding how, and to what extent, knowledge has evolved over time, the creation of new policies regarding best practices, as well as education and training plans, will be better informed.

Methods

The Fetal Alcohol Syndrome (FAS) Survey for Health Professionals (Clarke et al., 2005; PHAC, 2005a; Tough, Clarke, Hicks, & Clarren, 2004; Tough, Clarke, Hicks, & Clarren, 2005a, 2005b) is a questionnaire designed for Canadian health care professionals, including paediatricians, psychiatrists, midwives, family physicians, and obstetricians/gynaecologists. The questionnaire consists of four parts: general knowledge; prevention issues; diagnostic issues; and background information. The primary study was undertaken to obtain national information from physicians and midwives across Canada regarding their levels of knowledge, attitudes, and beliefs about FAS and related conditions. The questionnaire was available in English and French, and participants had the option to complete the survey as either a web-based version or in a paper format.

Data for the original national study were collected between March 2001 and October 2002. A random representative sample of 5,361 health care professionals were selected from membership lists, including the Canadian Paediatric Society, the National Association of Midwives, the College of Family Physicians of Canada, and the Society for Obstetricians and Gynaecologists of Canada. The

overall participation rate for the national study was 41.3% (PHAC, 2005a), resulting in a sample size of 2,216 health care professionals. For the purposes of this study, only the Ontario specific data are examined. Ethics approval was sought from the principal investigators of the original study and permission was given to access the de-identified, Ontario specific data from the national study. In addition, ethical approval for this study was obtained from the Laurentian University Ethics Board, Ontario, Canada, and is in line with the Canadian Tri-Council Recommendations for Research with Human Participants.

A total of 884 participants from Ontario completed the FAS Survey for Health Professionals. After screening the data, health care professionals who did not indicate their medical specialty or specify whether they considered their practice to be urban or rural were removed from the analyses. Participants who included multiple answers, entering that they perceived their practice to be both rural and urban, were also removed from the analyses. In total, fifty participants were removed, leaving a final sample of 834 participants. Information outlining participant areas of specialty and demographics can be found in Table 1.

Table 1. Participant Demographic Characteristics

<i>Demographic Characteristics</i>		
Health care provider (<i>n</i>)		834
Paediatrician (%)	276	(33.1)
Psychiatrist (%)	168	(20.1)
Midwife (%)	56	(6.7)
Family Physician (%)	278	(33.3)
Obstetrician/Gynaecologist (%)	56	(6.7)
Average age (<i>SD</i>)	46.2	(10.6)
Urban (<i>Rural</i>) (%)	84.2	(15.8)
Southern (<i>Northern</i> ^a) (%)	94.0	(6.0)
Male (<i>Female</i>) (%)	52.0	(48.0)
English (<i>French</i>) (%)	99.4	(0.6)
Percentage of Practice ^b (%)		
Aboriginal		6.0
Women (16+)		43.9
Children (≤15)		43.8

Note: a = provider practicing in Northern Ontario defined as any region north of Parry Sound

b = Percentage does not equal 100, as providers could indicate that their practice covers more than one area

Data were analyzed using Statistical Package for the Social Sciences (SPSS)/PC Version 20.0. Descriptive analyses and chi-square tests were performed to better understand this sample of health care professionals, as well as their knowledge, attitudes, and practices related to FASD. Data were pooled for analyses and individual responses were not identifiable. Participant responses to open-ended questions were also examined and analyzed using a thematic analysis approach (Braun & Clarke, 2006) to identify patterns and themes from participant comments.

Results

The results presented in this paper focus on the province of Ontario, given the recent emphasis from families of children with FASD who report being unsatisfied with health care providers' knowledge of FASD (Coons, Watson, Schinke, & Yantzi, 2016; Coons, Watson, Yantzi, & Schinke, 2016). Results for the national sample have been presented elsewhere (see PHAC, 2005a).

Health Care Provider Knowledge and Awareness

When asked whether they had previously heard of FAS, nearly all (99.5%) of survey respondents replied "yes." In addition, the vast majority of professionals (98.4%) reported first learning about FAS more than four years ago. When considering their own personal practice within the past five years, professionals were asked

if, in their practice, they had ever diagnosed a patient as having FAS, cared for a patient with FAS, suspected, but did not diagnose, a patient as having FAS, or referred a patient to confirm a diagnosis of FAS. About 40.4% of individuals indicated that they had cared for patients affected by FAS and 30.2% confirmed that they had personally diagnosed patients with FAS in their professional practice.

Participants were also asked about their perceptions of barriers to the diagnosis of FAS (see Table 2). Over a quarter of professionals indicated that diagnosing FAS was outside of their role. Interestingly, while the majority of professionals indicated that diagnosing FAS was within their scope of practice, 16% of paediatricians (compared to 15.1% of paediatricians nationally; PHAC, 2005a) and 24.5% of family physicians (compared to 23% of family physicians nationally; PHAC, 2005a) indicated that making a diagnosis of FAS was beyond their professional responsibilities, two populations that would likely be involved in the decision to diagnose a child with FAS. It is possible that family physicians may initially suspect an FASD, but may make a referral to a specialist to confirm the diagnosis, particularly in certain cases. Obstetricians and gynaecologists did not indicate that diagnosing FAS was outside of their role as practitioners, but disagreed that any of the listed factors were barriers to diagnosing. Not surprisingly, most midwives (64.3%) indicated that diagnosing FAS was separate from their range of care, given that the focus of their work does not include long term follow up with the mother or the child.

Table 2. Barriers to Diagnosis of FAS by Professional Group

	<i>Is making a diagnosis of FAS beyond the scope of your practice?</i>		<i>Lack of time needed to make a diagnosis</i>		<i>Lack of specific training to make a diagnosis</i>		<i>Belief that making the diagnosis will not make a difference to the individual</i>		<i>Other reasons</i>	
	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Paediatrician	16.3	83.7	20.9	79.1	67.6	32.4	13.4	86.6	11.6	88.4
Psychiatrist	39.9	60.1	9.9	90.1	47.9	52.1	13.6	86.4	8.0	92.0
Midwife	64.3	35.7	3.9	96.1	23.5	76.5	3.9	96.1	2.0	98.0
Family Physician	24.5	75.5	24.2	75.8	70.4	29.6	11.9	88.1	4.0	96.0
Ob/Gyn	0.0	100.0	0.0	100.0	0.0	100.0	0.0	100.0	0.0	100.0
All Groups	27.7	72.3	17.3	82.7	57.2	42.8	11.4	88.6	6.9	93.1

Nearly three-quarters of family physicians (70.4%) agreed that a lack of specific training was a barrier to the diagnosis of FAS, compared to 23.5% of midwives. However, only 11.4% of interviewed professionals believed that making the diagnosis would not make a difference for the individual with FASD. Several health care professionals listed other reasons that may impede the diagnosis of FAS including: social stigma; the diagnosis is difficult and unreliable; the facial characteristics and physical features can be ambiguous; a lack of truthful or accurate history of maternal drinking; a fear of over-diagnosing a condition; full syndrome FAS compared to FAE is not common in community practice; do not see patients with FAS/FAE or do not see enough patients with FAS/FAE; and parental resistance, denial, and anger to receiving the diagnosis. Some professionals also noted their own lack of experience and lack of knowledge of FASD.

When professionals were asked from what sources they have gained knowledge about FAS and FAE, 63.8% of health care providers reported obtaining knowledge of FASD from either medical school, a residency, or a fellowship; however, this proportion dropped to 51.8% and 25% respectively for psychiatrists and midwives. Other sources from which professionals obtained their knowledge of FASD included medical journals and books (78.9%), mass media (44.2%), colleagues (41.0%), and parents/patients (19.8%). However, when considering rural health care providers specifically, a greater proportion of these individuals gained information from more informal sources, such as mass media (53.0%), colleagues (50.0%), and parents/patients (27.3%).

What Advice Do Providers Give?

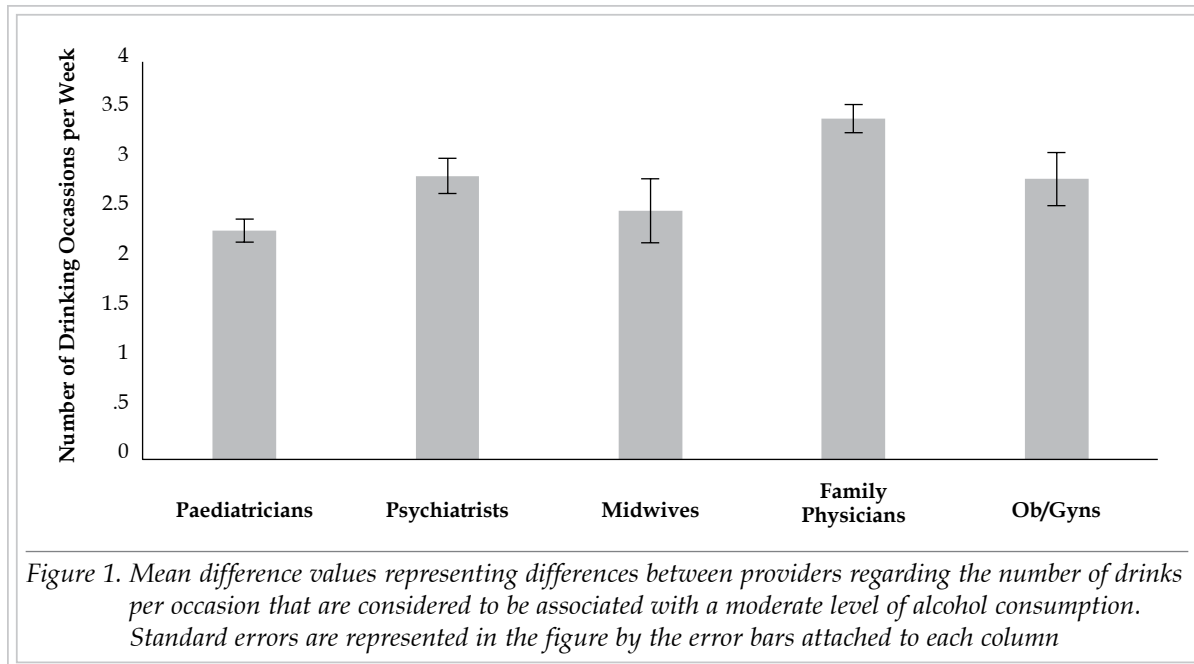
Approximately 3 out of 4 (73.2%) surveyed health care providers responded that they discuss the risks of alcohol consumption during pregnancy with female patients of childbearing age. Only 5% of health care providers believed that discussing alcohol use during pregnancy will frighten or anger patients. In addition, although 93.7% of those surveyed agreed that they asked all pregnant women in their care whether they were currently drinking alcohol, only 87.9% of respondents recommended complete abstinence from alcohol during pregnancy, indicating that 12.1% of respondents still condoned or recommended some level of alcohol

consumption during pregnancy. Furthermore, while 87.9% of respondents agreed with the statement that “no alcohol is recommended,” differences in the interpretation of the question potentially leave room for other recommendations or suggestions to patients (e.g., no alcohol is recommended, but occasional consumption may not pose any risks). Also troubling is the finding that not all participants agreed (92.2%) that prenatal alcohol exposure poses a significant risk for permanent brain damage.

Nearly 1 in 10 health care professionals provided counsel other than abstaining from alcohol during pregnancy, including “a glass of beer or wine in moderation was okay” (8.8% of respondents), or offered no specific suggestions in regards to prenatal alcohol consumption. Furthermore, only 80.5% of participants acknowledged that they discuss what their patients think “in moderation” means (e.g., a range of 3 to 13 drinks per week). While many participants condoned moderate alcohol consumption, they struggled to provide a consistent definition of what “moderation” meant.

“I do not use the term ‘in moderation’”: Defining Moderate Alcohol Consumption

Of the professionals who completed the survey, only 62.4% agreed with the practice of telling patients (both male and female) to drink in “moderation.” However, little consistency existed around the definition of “moderation.” One-way ANOVAs were performed in order to determine differences between health care professionals’ specialties and their definition of “moderate alcohol consumption” in terms of both the reported number of drinks per occasion and the reported number of drinking occasions per week for non-pregnant women. No significant differences were found between professional specialties in terms of drinks per occasion (although significance was approached – $p = .062$); however, family physicians ($M = 3.44$, $SD = 2.32$) reported a significantly higher number of drinking occasions per week as “moderate alcohol consumption” when compared to paediatricians ($M = 2.31$, $SD = 1.90$) and midwives ($M = 2.51$, $SD = 2.36$) ($F_{(4, 787)} = 9.42$, $p < .001$, see Figure 1). Bonferroni post-hocs revealed that no other differences existed between professional specialties.



Participant responses to open-ended questions also indicated confusion over a definition of “moderate” alcohol consumption. Some participants indicated that “we do not know what a moderate level is” and that they were “uncertain if any level is ‘safe’ at any time of pregnancy.” However, other participants indicated that “occasional alcohol use” or alcohol consumption “1-2 times per week” was a moderate level of consumption. In addition to discrepancies in professionals’ definitions of moderate alcohol consumption for non-pregnant women, professionals reported many exceptions and situation-specific recommendations concerning best practices and guidelines for pregnant women regarding alcohol use during pregnancy.

**“One or three, depends on the patient”:
Inconsistent Recommendations**

Participants were provided with five choices and asked which statement best describes the advice they give pregnant women regarding alcohol use during pregnancy. 12.2% of health care professionals indicated providing a recommendation other than abstinence from alcohol consumption during pregnancy. Health care professionals specified many instances that they perceived to be acceptable (or unacceptable), including existing stereotypes of FASD

(e.g., FAS only occurs in patients who have alcohol use problems), occasional drinking across different trimesters, differing amounts of alcohol consumption (e.g., low dose exposure), and drinking on special occasions.

“If no history of alcohol abuse, I say OK in moderation”: FASD stereotypes. Several participants prescribed to the stereotypical belief that FAS and FASD are particularly problematic only for women with alcohol use issues. One participant noted that “an occasional glass of wine or beer is okay. Unless [the] person is truly an alcoholic, then I recommend none,” demonstrating that some professionals may condone occasional drinking during pregnancy for women who they perceive to not be alcoholics. In the open-ended responses, participants also discussed that binge drinking was particularly dangerous, especially for women who were high risk.

“Occasional drink is fine only after first trimester”: Perceived differences across trimesters and timing of exposure. While some health care professionals acknowledged that binge drinking is “never okay” and is “dangerous” at all times during pregnancy, when asked to provide open-ended responses, numerous professionals reported that occasional or moderate drinking was “fine only after [the] first trimester.” One professional noted that

their definition of moderation was “abstinence in [the] first trimester.” Several professionals echoed these remarks, stating that alcohol should be avoided during the first trimester, but that “occasional use throughout (i.e., one drink per occasion) will not harm mom or baby” and that “once passed first trimester, patient can have occasional drink, one drink per week or so.” One family physician indicated that “up to one to two drinks, one to two times a week throughout all trimesters is OK.”

Some professionals also identified challenges regarding addressing alcohol consumption before pregnancy identification. One physician noted that they “try to assure women who report occasional alcohol use in first weeks of pregnancy before knowing about pregnancy” in an effort to prevent feelings of panic or guilt. However, several professionals believed that “limited or moderate exposure before pregnancy diagnosed [is] not supported as high risk” and “a few drinks before know[ing] about pregnancy is okay.”

“But no harm shown for occasional consumption”: Amount of alcohol consumption. Closely tied to the discrepancy regarding the timing of exposure is the debate regarding the acceptable amount of alcohol exposure during pregnancy. Many physicians who did condone alcohol consumption during pregnancy indicated that drinking should be “occasional,” “rare,” and should only include “very limited alcohol,” “one drink,” or a “half glass.” However, no statements included a definition of what “one drink” entailed and no professionals identified that “one drink” should be a standard drink. Professionals also provided varying responses regarding the amount of alcohol that should be consumed during a week or during the duration of pregnancy. For example, professionals’ diverse responses included “two drinks per week,” “one to two glasses of wine during pregnancy,” “maximum one drink per week,” “half glass maximum per week,” “half only per day,” and “one drink, three to four times per week.”

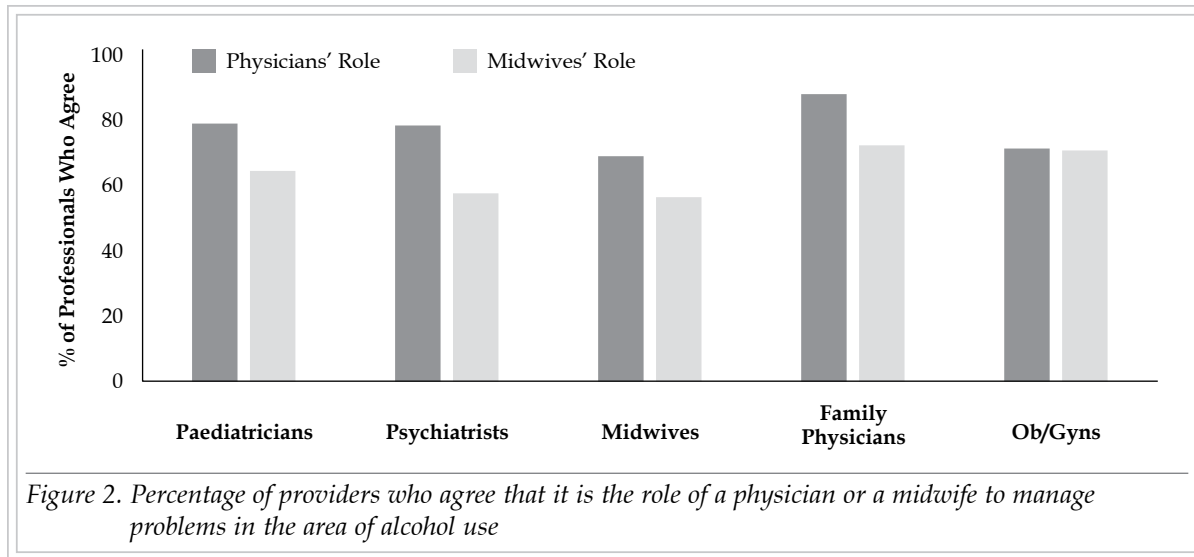
“Occasional drink for special occasion only”: Perceived exceptions. When asked which recommendation best describes the advice that professionals give to pregnant women regarding alcohol use during pregnancy, the most common “other” response that profes-

sionals gave was that alcohol consumption was acceptable for special occasions only. Birthdays, anniversaries, and Christmas were some of the notable special occasions included. Again, responses varied regarding how much should be consumed on these special occasions. Responses included: “one glass of beer or wine for special occasion and not more than one drink per week,” “occasional drink,” “a sip of wine or beer,” “one half glass of champagne or wine for a celebration, not more than once a week,” and “one glass on wedding anniversary.” While some professionals did indicate that “there is no safe quantity of alcohol determined for pregnant women,” and in order to “err on the side of caution, no alcohol should be consumed,” these responses were rather limited in the open-ended responses ($n = 12$).

Health Care Provider Differences

Chi-squared analyses were performed to determine whether health care providers felt that managing problems in the area of alcohol use was either the responsibility of the physician or the midwife (see Figure 2). Physicians and midwives were asked to what degree (e.g., strongly agree, agree, disagree, strongly disagree) they perceived it to be the physician’s role or the midwife’s role to manage problems in the area of alcohol use. Significant differences existed between the responses of health care providers when asked whether it was the responsibility of the physician to manage patients’ problems in the area of alcohol use [$\chi^2 (8, n = 826) = 19.28, p = .013$]. Most family physicians (88.1%) agreed with the statement, whereas only 69.2% of midwives agreed with this statement. Also of note was that 5.3% of respondents were undecided as to whether it was the responsibility of the physician or not.

When considering whether midwives were responsible for managing problems in the area of alcohol use, significant differences were also found [$\chi^2 (8, n = 822) = 16.63, p = .034$]. Interestingly, a large number of physicians (72.5%) also agreed that it was the midwives’ responsibility, and once again, fewer midwives endorsed the same statement (56.6%). In this case, 9.0% of those who completed the survey were unsure as to whether or not it was the responsibility of the midwife to deal with patients’ alcohol use problems.



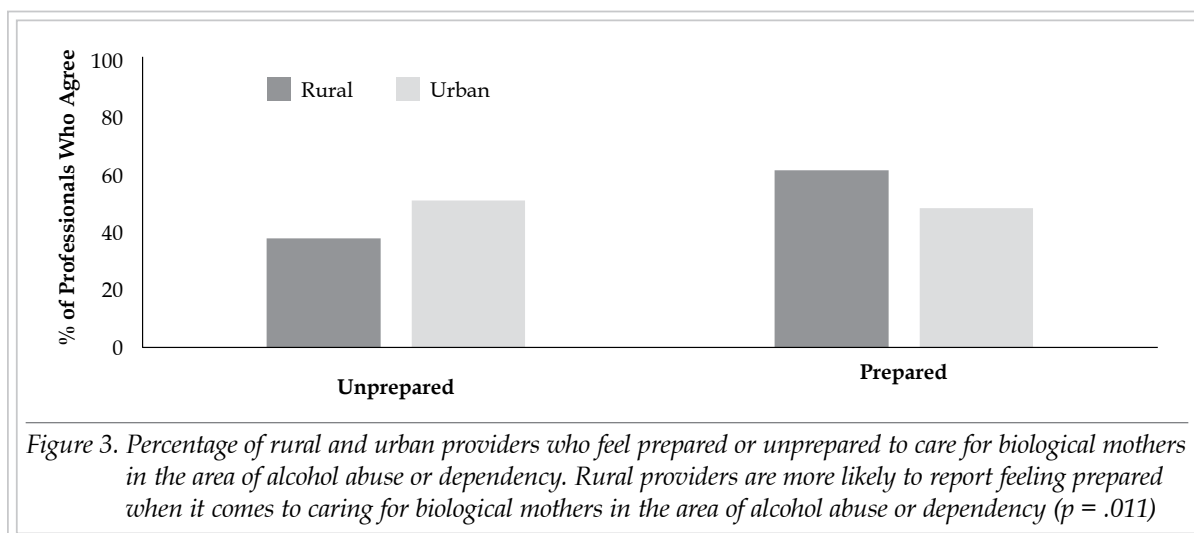
Rural and Urban Provider Differences

Location of practice, whether in a rural or urban setting, and its influence on whether professionals asked all pregnant patients about their drinking habits (i.e., if currently drinking alcohol) was determined using chi-squared analyses. The results indicated that a significantly greater proportion of rural health care providers (99.1%) asked their pregnant patients about their alcohol use when compared to urban providers (91.6%) [$\chi^2 (1, n = 382) = 7.34, p = .007$].

Chi-squared analyses were also performed to determine differences between rural and urban health care providers in terms of diagnosing

FAS in patients as well as caring for patients affected by FAS as part of their practice. Results suggested that the proportion of rural and urban professionals who reported diagnosing FAS in patients was not significantly different. In contrast, a significantly greater proportion of rural providers (49.6%) reported caring for patients affected by FAS in their practice compared to their urban counterparts (38.8%) [$\chi^2 (1, n = 769) = 4.78, p = .029$].

Additional analyses indicated that more rural professionals (61.9%) felt prepared to care for birth mothers in the area of alcohol use or dependency than those practicing in urban settings (48.7%) [$\chi^2 (1, n = 620) = 6.47, p = .011$] (See Figure 3). Individuals within the following



professional groups in rural settings, including obstetricians/gynaecologists (83.3%) and family physicians (65.3%), indicated feeling more prepared to care for birth mothers, compared to psychiatrists (42.9%), paediatricians (42.9%), and midwives (30.8%). However, no significant differences were found between rural and urban health care providers' preparedness to care for pregnant women (rural: 58.4%, urban: 49.6%) or individuals affected by FAS in the area of alcohol use or dependency (rural: 50.4%, urban: 47.1%).

Discussion

The authors of this secondary data analysis found that, in general, health care professionals in Ontario were aware of FASD. However, some professionals did not believe that alcohol exposure during pregnancy is a significant risk for brain damage and did not agree that abstinence from alcohol during pregnancy is the best recommendation for women. The authors also found that some confusion existed regarding scope of practice in addressing and diagnosing FASD. For example, one quarter of participants indicated that diagnosing FAS was beyond their professions' responsibility and over half of participants indicated that lack of specific training was a critical barrier to diagnosis and knowledge of FAS and FASD. Participants also identified various sources from which they obtained their information regarding FAS and FAE, including from the mass media and from parents and individuals with FASD, which have implications for the quality and accuracy of information that they receive about FASD.

The finding that not all health care providers recommended complete abstinence during pregnancy is the most disconcerting result from this secondary data analysis. While 87.9% of surveyed Ontario health care professionals agreed with the statement that no alcohol is recommended during pregnancy, compared to 87.5% of professionals who responded to the national survey (PHAC, 2005a), more than 1 in 10 providers did not agree with this statement and cited exceptions to this recommendation (e.g., occasional or light drinking is likely not dangerous, drinking during pregnancy is only problematic for women with alcohol use problems). Also of concern is that several providers who did agree with the recommendation that

no alcohol is recommended gave open-ended responses indicating that there are sometimes exceptions or circumstances where occasional or moderate drinking is acceptable (e.g., drinking on special occasions). These findings suggest that professionals may not be providing consistent and clear recommendations to all pregnant women or women of childbearing age.

Women of childbearing age, whether planning on becoming pregnant or not, should be informed of the risks of alcohol consumption during pregnancy. However, challenges exist if health care providers are unaware of, or do not apply, recommended clinical practice guidelines. For example, the Public Health Agency of Canada (2005b) recommends a better implementation strategy of the existing clinical practice guidelines advocating that no alcohol be consumed during pregnancy. These suggestions mirror the recommendations of the Canadian Centre on Substance Abuse (Finnegan, 2013) for *Canada's Low Risk Drinking Guidelines*. Unfortunately, inconsistent public health policy and varying standards can create confusion as to which recommendations professionals should follow. It is also important to note that these data were collected before these strategies were established.

In 2010, the Journal of Obstetrics and Gynaecology of Canada, in conjunction with the Canadian Association of Midwives, the Association of Obstetricians, the College of Family Physicians of Canada, and the Society of Rural Physicians of Canada, published the *Alcohol Use and Pregnancy Consensus Guidelines* (The Society of Obstetricians and Gynaecologists of Canada [SOGC], 2010). The SOGC refer to themselves as the 'official voice of reproductive health care in Canada' (SOGC, 2010). In the clinical guidelines, the SOGC determined that there is evidence that alcohol consumption during pregnancy can cause fetal harm. However, the SOGC concluded that there is insufficient evidence regarding fetal safety or harm at low levels of alcohol consumption during pregnancy (SOGC, 2010). In rat models, Goodlett, Marcussen, and West (1990) demonstrated that a single exposure to alcohol in late pregnancy could cause a severe loss of brain cells. More recently, findings from a longitudinal study of 607 individuals prenatally exposed

to alcohol demonstrated that alcohol exposure at each trimester predicted increased behaviour problems. The authors conclude “there is no safe level or safe time during pregnancy for women to drink” (Day, Helsel, Sonon, & Goldschmidt, 2013, p. 1). While the SOGC does recommend that abstinence is the cautious choice for a woman who is or might become pregnant, considerable debate still exists regarding low levels of alcohol consumption during pregnancy. Inconsistent messaging can lead to confusion between research evidence and suggested practices, and may partly explain the participants’ mixed responses in this study.

Despite an identified need to address alcohol consumption during pregnancy and FASD, Canadian findings suggest that less than half of family physicians discussed the risks of alcohol use, drug use, or smoking during pregnancy with women of childbearing age (PHAC, 2005a; Tough et al., 2005a). Only 73.2% of health care professionals in this study reported that they discussed the risks of alcohol consumption during pregnancy with female patients of childbearing age; however, this proportion is nearly twice the national frequency of 40.1% (PHAC, 2005a). These findings suggest that improvements in information exchange between health care professionals and patients on key health issues may be warranted, in particular clarifying the definition of moderate alcohol consumption and the repercussions of alcohol and drug use during the prenatal period and/or pregnancy. Less than half of health care professionals in Canada reported frequently discussing these issues with women of childbearing age (Tough et al., 2005a).

Providing clear and consistent information to women is also critical (Raymond, Beer, Glazebrook, & Sayal, 2009), as a “faulty information delivery system” (Anderson, Hure, Kay-Lambkin, & Loxton, 2014, p. 5) between the provider and the patient can lead to varying perceptions and interpretations about ‘safe levels’ of alcohol consumption during pregnancy. Anderson et al. (2014) found that when women received various and conflicting information regarding alcohol use during pregnancy, they created a hierarchy of information, often relying on health care providers to explain these discrepancies. Women not only view their health care provider as a reliable source of informa-

tion, but also believe they hold *expert* knowledge (Anderson et al., 2014). Therefore, if health care professionals are ill-informed about the risks of prenatal alcohol exposure or do not provide their patients with valid information (e.g., if they condone moderate or light drinking or indicate that alcohol is only dangerous during the first trimester), professionals are potentially increasing their patients’ risks of having a child with a FASD.

It is also important to understand where professionals are obtaining their information regarding FASD. Almost half (44.2%) of health care professionals in general, and over half (53%) of rural professionals specifically, in this study identified that they received their information about FASD from the mass media. Trusting potentially unreliable sources can be problematic, given the recent social movement towards encouraging mild to moderate alcohol use during pregnancy. For example, economist Emily Oster’s book, *“Expecting Better: Why Conventional Pregnancy Wisdom Is Wrong – and What you Really Need to Know,”* created considerable controversy in 2013 when she concluded that current research shows that it is harmless to drink a limited amount of alcohol during pregnancy. Michelle Ruiz also generated debate with her *Cosmopolitan* article in October of 2014 entitled *“Why I Drank While I Was Pregnant.”* Both media sources cite highly criticized research and conclude that light to moderate drinking during pregnancy poses no risk to the fetus.

This movement is concerning, given research trends that demonstrate that health care professionals are increasingly accessing their information about FASD from mass media sources, as also demonstrated by the results of this study. For example, Payne et al. (2011a) noted that obstetricians and gynaecologists, in particular, cite the media as one of their main sources of information. Additional research has also shown that an increasing proportion of paediatricians report being informed about alcohol use during pregnancy by the media (Payne et al., 2011b). While the majority of health care professionals continue to gain knowledge about FAS and FASD from journals and books (Payne et al., 2011a), fewer professionals, compared to an earlier study of the same population, reported gaining their knowledge of FASD from scientific, peer-reviewed journals and books (Payne

et al., 2011b). These findings indicate a need to disseminate accurate information, in a useful format, through the media.

Importantly, some health care professionals in this study also indicated accessing information regarding FASD from parents and patients with FASD, but the percentages of professionals who did so were rather low, with only 19.8% of professionals in general and 27.3% of professionals practicing in rural communities indicating that they obtained information in this way (compared to 24.1% of respondents in the national survey results; PHAC, 2005a). These percentages may speak to the challenges reported by families of children with FASD who express their frustrations at not being heard by their child's health care provider and frequently cite these professionals as being unsupportive (Coons et al., 2016; Watson et al., 2013).

Health care professionals in this study also identified that there was confusion and overlap surrounding whose role it is to manage FASD. Because FASD crosses many sectors of society (e.g., health, education, social services), and individuals with FASD and their families access many different health care providers, these varying perspectives may be, in part, related to challenges determining whose scope of practice it is to primarily address FASD. These varying perspectives are also likely due to the fact that, depending on the patient's circumstances (e.g., pre-partum or postpartum), diverse providers may play the primary role. For example, midwives and obstetricians or gynaecologists play an important role in the primary prevention of FASD and are responsible for a woman's health during pregnancy and immediately afterwards. Different timings of responsibility may account for the finding that a smaller proportion of midwives agreed that it was their responsibility (56.6%) than those who agreed it was the physician's responsibility (69.2%). However, a large proportion of midwives still agreed that it was their role, indicating that some professionals may feel that it is not the sole responsibility of any individual health care provider to manage FASD. The importance of role clarity is crucial as a clear understanding surrounding one another's roles and responsibilities promotes successful interprofessional collaborations between physicians and midwives (Munro, Kornelsen, & Grzybowski, 2013). Contrastingly, Munro and colleagues (2013) found that a lack of understanding between physicians and mid-

wives regarding each other's scope of practice could lead to challenges in providing interdisciplinary care to pregnant women, especially in rural communities.

Furthermore, paediatricians and family physicians may also play a more central position in directly managing the individual with FASD, as opposed to a woman of childbearing age or a pregnant woman. Research has demonstrated that paediatricians are often called on to provide a medical home for children with FASD, and therefore are responsible for coordinating mental health services, providing consultations to special education programs, and managing medications for attention deficit hyperactivity disorder or other comorbid mental health disorders (Gahagan et al., 2006).

Findings from this study also demonstrated some variability in health care professionals' experiences in diagnosing FAS. Many professionals indicated that diagnosing FAS was beyond their scope of practice, and cited a number of barriers that can impede their ability to diagnose FAS. Research findings from Gahagan et al. (2006) showed that paediatricians may specifically express a reluctance to concentrate their efforts on diagnosing FASD, as they perceive it to be an untreatable condition. Future medical education should include known benefits of early diagnosis and intervention for children with FAS and FASD, such as the potential for preventing secondary disabilities.

Finally, findings from this study also indicated that rural health care professionals asked more of their pregnant patients about their alcohol use, cared for more patients with FAS in their practice, and felt more prepared in particular situations (e.g., to care for birth mothers), compared to their urban counterparts. The scarcity of paediatric specialists in rural areas could lead to other health care providers treating patients with FASD in their daily practice. In other practice settings, such as larger urban centres, professionals may be more likely to refer their patients to see a specialist (e.g., geneticist, developmental-behavioural paediatrician, or neurologist) for additional evaluation or assessment if necessary (Gahagan et al., 2006). Rural professionals may also have more training and more experience in the area of FASD, as they are expected to have more generalized practices and generally see more patients. This preparedness is likely due to

rural providers having more exposure to individuals with FASD (attributable to the higher prevalence rates in rural areas), as well as rural providers seeing more patients with FASD than their urban counterparts (Tough et al., 2008).

Limitations and Future Directions

Although this study was the first study to address the level of knowledge of FASD held by rural and urban Ontario health care professionals, a number of limitations presented, predominantly the age of the data used for the secondary data analysis. These data are 15 years old, and as such may not reflect the current level of knowledge held by practicing health care professionals today. This study should be updated, utilizing the original data as a baseline for comparisons, and additional research should be conducted to determine the level of knowledge of FASD held by health care professionals in Ontario today. Additional research should also examine the level of knowledge of FASD held by future health care professionals to determine if students are adequately educated about FASD during their medical training. Future research should also address health care students' and health care professionals' feelings of self-efficacy in working with women of childbearing age, pregnant women, and individuals with FASD.

Because of the age of the original data collected, there are also differences in the terminology used (e.g., FAS, FAE). The term FASD is now used as a diagnostic label, with the differentiation of FASD with and without sentinel facial features (Cook et al., 2015). The new diagnostic guidelines also include an at risk category for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure (Cook et al., 2015). Health care professionals today may have a different level of knowledge of FASD, given the changing terminology of the disabilities included under the spectrum. However, research has shown that health care professionals do tend to have better knowledge of FAS compared to other disabilities on the fetal alcohol spectrum, which may be influenced by a focus on FAS specifically in medical education or the overshadowing of FASD as a topic in medical education (Nanson, Bolaria, Snyder, Morse, & Weiner, 1995). Additionally, because of the changing terminology, some of the issues identified in this study (e.g., changing diagnostic criteria) have likely been lessened since the time the original study was published. The role of pro-

fessional counselling in primary prevention of FASD should continue to be stressed in medical education curricula, so that future generations of providers will incorporate these principles into their practice (Zoorob, Aliyu, & Hayes, 2010).

In addition to the age of the data, the original study did not include an operational definition of rural. Health care professionals were asked to indicate whether or not they perceived their practice to be rural or urban. This self-perception created some confusion, as a number of providers indicated their practice was both rural and urban. In line with recent rural health research, future research with this population should include an operational definition of rural, as different definitions generate a different number of rural people or professionals. Despite its limitations, this study used a large sample size and a very thorough survey to demonstrate the level of knowledge held by health care professionals in Ontario.

Conclusion

FASD is a preventable disability and health care professionals play a key role in its prevention; however, results from this secondary data analysis indicate that many physicians, midwives, and other health care professionals may have inconsistent knowledge regarding the impact of prenatal alcohol exposure. Consequently, women of childbearing age may be receiving mixed messages from health care professionals, resulting in confusion and potentially harmful behaviours. Clear, consistent recommendations regarding alcohol use during pregnancy are required in order to prevent FASD and its potentially devastating effects. By understanding the knowledge deficits of health care professionals, these gaps can be targeted and subsequently addressed in health care education and training.

Key Messages From This Article

People with disabilities. You should have access to educated health care professionals who are aware and understand your disability. You should also feel confident and comfortable with the level of care provided by the doctors that you see.

Professionals. FASD is a preventable disability that you have a critical role in preventing. Professionals need to be educated about FASD and provide accurate advice to preg-

nant women. Professionals need to be wary of the information they obtain from the mass media; information regarding FASD should be obtained from more scientific sources.

Policymakers. FASD is a preventable disability. Ontario needs a provincial strategy to address and prevent FASD. This strategy should include educating health care professionals about FASD as a major priority.

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