THE MOTHERISK ALCOHOL AND SUBSTANCE USE HELPLINE: 10 YEARS OF EXPERIENCE AND COUNTING

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The Alcohol and Substance use Helpline; The Motherisk Program, The Hospital for Sick Children, Toronto, Canada

ABSTRACT

The Motherisk Alcohol and Substance Use Helpline at The Hospital for Sick Children in Toronto, Canada, is a unique telephone service providing evidence-based information on the negative effects associated with alcohol and substance use in pregnancy and lactation. We describe the characteristics of the service, the demographics of the callers, and the inquiries made during its first ten years of service.

Since its inception in November 1998 until November 2008, almost 20,000 calls had been received with 60% of calls initiated by pregnant and breastfeeding women, the remainder from various health care providers. Most women exposed to alcohol and substances were of Caucasian descent (80%), employed (65%), and married (46%) with some level of post-secondary education (52%). The demographics of the callers deviate from the well-documented cohort of women at risk of engaging in alcohol and substance use in pregnancy and lactation, confirming that a selective group of women is more likely to use the services offered by the Motherisk program. Thus, further efforts are required to reach out to the subgroup of women at high risk of continuing their harmful behaviors during pregnancy and lactation.

Key Words: *Alcohol; pregnancy; fetal alcohol spectrum disorder; substance use; childbearing age*

Alcohol consumption is a wide spread social behavior with reported use by 77% of Canadian women 15 years and older.[1] Other substances such as tobacco and illicit drugs are also used recreationally by many women of childbearing age. Reports indicate that 17% of females are smokers[2] and 10% of females use marijuana in Canada.[1]

With half of all pregnancies unplanned[3], exposures to alcohol and other substances during early pregnancy is inevitable. Women using these substances may be exposed to significant levels of harmful chemicals due to a high prevalence of unplanned pregnancy[4], and delayed pregnancy recognition in this population.[5]

Alcohol and Recreational Drug use in Pregnancy

Alcohol and substance use in pregnancy is a major public health concern with numerous reports of adverse maternal and neonatal outcomes following gestational exposures.[6-9] Fetal Alcohol Spectrum Disorder (FASD) describes the physical and neurological abnormalities resulting from prenatal exposure to alcohol with symptoms ranging from neurobehavioral and neurocognitive deficits to facial dysmorphology.[10] Cigarette smoking in pregnancy increases the risk for spontaneous abortion, premature labor, low birth weight, and sudden infant death syndrome (SIDS).[11-15] Other substances have been associated with adverse pregnancy outcome with reports of intrauterine growth restriction and pregnancy complications.[16-19] Apart from the physical abnormalities reported in several studies, the developing fetal brain may particularly be vulnerable to prenatal insult of substance use.[20,21]

For many women, pregnancy represents a time of high motivation and interest toward the well being of their unborn child. Therefore, pregnancy offers a unique window of opportunity

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in engaging women with substance use problems, and addressing the concerns associated with their substance use.

Barriers in Screening

There are well-documented difficulties in identifying individuals with problem drinking and substance use, which has been a major barrier in providing women with the appropriate care.[22-24] Underreporting or denial of illicit drug exposure is common due to social stigma, feelings of guilt, embarrassment, and fear of losing custody. This problem is further intensified due to the inconsistency in addressing concerns regarding alcohol and substance use in pregnancy in primary care settings. Many health care professionals express feeling uncomfortable in routine screening for alcohol and recreational drug use in pregnant patients.[25-28] The main reasons are a lack of training and knowledge, inadequate awareness of effective screening tools, lack of information on referral sources, and insufficient time.

The third obstacle in caring for pregnant women with problem drinking and substance use, stems from the lack of national consensus and guidelines to recommend efficient screening methods.[29]

The Motherisk Program at the Hospital for Sick Children

The Motherisk Program is the largest teratogen information center in the world, providing evidence-based information regarding risks associated with exposures during preconception, pregnancy and breastfeeding. In November 1998, a specialized helpline focusing on substance use in pregnancy was created. Women with alcohol and substance use clearly have different needs than women exposed to prescribed medications. They are often guarded, anxious and reluctant to provide information about their use - therefore a special effort to engage the callers is needed. The duration of the call is significantly longer compared to inquiries regarding medication use in pregnancy. Some of the women also have other risk factors surrounding alcohol and substance use, and require further support services within their communities.

In an effort to address the damage incurred by a mother's alcohol and substance use in pregnancy and lactation, and to overcome the societal barriers mentioned above, the Motherisk Alcohol and Substance Use Helpline (1-877-FAS-INFO), a specialized information phone line was established. We aim to apply all available resources to informed risk management, prevent voluntary abortions caused by misinformation, and advocate knowledge and education as preventive measures.

Characteristics of the Helpline

The Motherisk Alcohol and Substance Use Helpline is a national toll free line accessible from Monday to Friday 9am-5pm within all time zones in Canada. The Helpline provides non-judgmental, evidence-based counseling, both in French and in English. The callers can be assured that the information provided is strictly confidential, and if preferred, anonymous.

Although the inaccuracy of self-report has been largely described, some studies report higher levels of participation and disclosure over the telephone than in face-to-face interviews.[22-24] Because the counseling process involves disclosure of sensitive information, telephone interviewing may offer advantages over face-to-face methods.[30-32] A telephone conversation allows the opportunity to communicate without direct contact with another individual, which may reduce the feelings of fear, guilt and shame. Moreover, telephone systems are cost effective, and allow easy access over widespread geographical areas.

The Intake Process

Women's use of alcohol and non-therapeutic substances is a complex condition, with other possible perinatal risk factors surrounding the substance use.

The Motherisk intake form reflects the complexity of the issues with the collection of the following information.

1. Maternal age
2. Number of pregnancies
3. Time of pregnancy recognition
4. Prenatal vitamins
5. Paternal drug use
6. Previous emotional or drug counseling/treatment
7. Medical conditions (including psychiatric conditions and infectious diseases)
8. Past or current injection of drugs

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9. Demographics (employment, marital status, ethnicity, level of education)

Exposures to alcohol and/or recreational drugs are carefully recorded with details on the amount and date of exposure. Due to the potential bias of underreporting or denial, TWEAK (Tolerance, Worry Eye-opener, Amnesia, Cut down) is administered to further screen for potential problem drinkers who may have been masked during the initial screening process. Among the different screening instruments made available in the identification of at-risk drinkers, the T-ACE (Tolerance, Annoyed, Cut down, Eye-opener) and TWEAK tools have been specifically validated for use in pregnancy. T-ACE is a set of 4 questions regarding tolerance, close friends or relatives worrying about the drinking, and feeling the need to cut down the drinking. A score of 2 or more points out of 5 points is indicative of an at-risk drinker. TWEAK includes 5 questions similar to the T-ACE with a score of 2 or more points out of 7 points indicating individuals at risk of problem drinking.

The following data are invaluable in assessing women's problem alcohol and drug use and in evaluating surrounding co morbid factors, which may act in combination to produce poor maternal and neonatal outcome.

1. *Maternal Age*
   Teenage pregnancies are associated with adverse pregnancy outcome due to the increase prevalence of poor prenatal care and delayed initiation of prenatal care[33], whereas late maternal age is also associated with its own perinatal risks.[34]

2. *Number of Pregnancies*
   Reports indicate that multiparous women are more likely to use substances in subsequent pregnancies than primiparous women.[35]

3. *Time of Pregnancy Recognition*
   Time of pregnancy recognition is useful in determining the span of time when a mother might have been using drugs. The later a woman becomes aware of her pregnancy, the longer the time she may have been exposed to other high risk conditions.

4. *Prenatal Vitamins*
   Good prenatal care with vitamin supplementation has been associated with improved pregnancy outcome.[36] This may particularly be important in this population, who are likely to be deficient in essential nutrients and vitamins.[37]

5. *Partner Drug Use*
   Women with substance use issues are more likely to be living with a partner, who also experiences similar dependence issues.[38] History of physical and emotional abuse, neglect and violence are more prevalent in women with problematic consumption of alcohol and substances.[39,40]

6. *Psychiatric Illnesses*
   Depression and anxiety are often associated with substance use in pregnancy and treating these conditions may help women stop or reduce their use.[41-43] Additionally, substance use has also been associated with risky sexual behaviors resulting in sexually transmitted diseases such as of herpes, which can exert their own risks on the pregnancy.[44,45]

The Counseling Process

Counseling typically ranges from 15 minutes to more than one hour. Motherisk counselors are trained with motivational interviewing skills, as well as using validated methods of counseling in the treatment of substance use dependence. Motivational interviewing has proven to be a cost effective method, increasing motivation in individuals to change their harmful behavior, while experiencing minimal resistance in the counseling process. The effectiveness of the approach adopted comes from the non-confrontational, non-judgmental, women-centered approach.[47]

The Motherisk counselors provide evidence-based information to empower the callers in their own decision-making processes. An empathetic listening approach is also adopted, as it has been determined to be one of the strongest predictors to elicit behavioral changes in women with substance use.[48] In addition, a non-judgmental setting is provided, as the counselors

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understand the complex situations experienced by women with substance use issues.

In order to obtain detailed information regarding exposures, counselors avoid closed ended questions, which require a "yes" or "no" response.[29] Open-ended questions are useful in leaving the caller with the space to expand on the details of their alcohol and substance use.

Referral to other Services

The Motherisk Program is primarily an information providing service. However, helping individuals to reduce or stop their harmful behaviors is a complex task, and supporting these women involves more than just disseminating information regarding the risks associated with alcohol and drug exposures in pregnancy. Therefore, callers are offered information regarding supportive services in their community to address their individual needs. Many women with substance use may require supportive counseling, treatment centers, prenatal services, mental health care, employment centers, food bank and shelters. Referral to the Motherisk FASD clinic is made for children who have been exposed to alcohol in utero. The assessment involves an interdisciplinary team composed of a physician, a psychologist and an occupational therapist.

The Motherisk laboratory works closely with child protection agencies, by examining samples of hair and meconium to detect the use of alcohol and substances, in a pregnant or breastfeeding mother when child custody is at question.

RESEARCH

Advancing our current knowledge on the effects of maternal use of alcohol and substances in pregnancy and breastfeeding is an integral part of the Motherisk Program. With the participation and consent of women who have used the Helpline, Motherisk has conducted many studies on the topic of alcohol and substance use in pregnancy and breastfeeding. In addition to clinical research, Motherisk conducted a meta-analysis[49] aimed to improve our understanding of the effects of moderate alcohol consumption in pregnancy. A neurodevelopmental study on the offspring of women who engaged in alcohol binge episodes prior to pregnancy recognition reported a greater degree of disinhibited behavior.[50] A study on adopted children exposed to cocaine allowed follow up of the effects of cocaine independently from the environmental factors associated with cocaine use.[51] Moreover, several pregnancy and breastfeeding guidelines have been published concerning alcohol, cocaine, marijuana and methadone use.[52-55]

FACE (Fetal Alcohol Canadian Expertise) Research Roundtables is a group of researchers, program providers and stakeholders actively working in the prevention and intervention of FASD. Fetal Alcohol Research (FAR) journal is the official journal of the FACE Research Network that publishes the most recent advances in the field of alcohol and substance use in pregnancy. The following is a summary of some of the achievements of the Helpline in its first 10 years and counting of service.

Caller Characteristics

Between November 1998 and November 2008, the Motherisk Alcohol and Substance Use Helpline counseled 17,318 callers. This number does not include general questions pertaining to the Helpline or referrals to laboratories or inquiries regarding FASD assessment. The majority of the callers required information in English (93%), with only 7% of the callers requiring French.

The number of calls received has been stable over the last 10 years. The consistent increase in number of calls from 1998-2004 is clear evidence of the needs for a specialized helpline centered on the issues of alcohol and substance use in pregnancy and breastfeeding. After 2004, the increase in number of calls received per year has been less dramatic, which may in part be due to the wide spread awareness on the risk of alcohol consumption during pregnancy, and more accessible information via the internet.

Geographical Breakdown

More than 70% of the callers originated from Ontario, with calls from Quebec, British Columbia and Alberta representing 7.5%, 7% and 6% respectively. Interestingly, these provinces, where resources and support programs for alcohol and substance use in pregnancy are well

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established represented the highest percentage of calls outside Ontario. This may reflect the fact that provinces, where resources are widely available, are also more likely to be aware of services offered outside their own provinces.

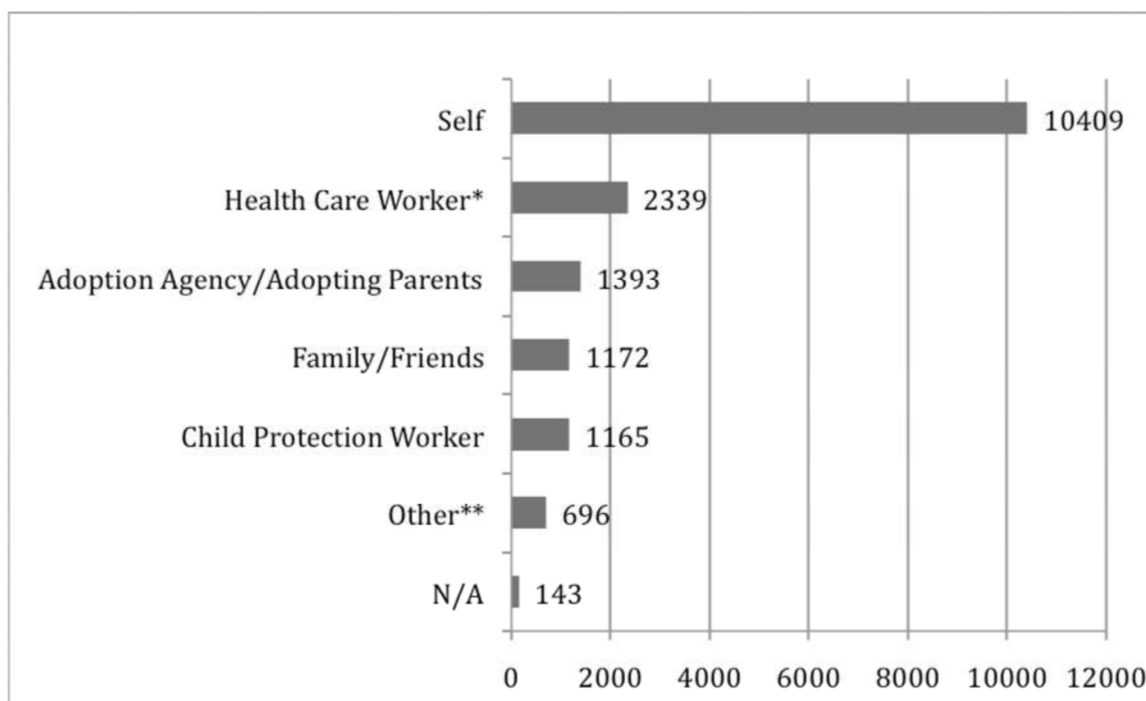
Perinatal Timeframe of Calls

53% of the callers required information on exposures during pregnancy, 19% of the callers were exposed during breastfeeding and 8% involved retrospective cases. Only 2% of the callers were inquiring about exposure during pregnancy planning period. Indeed, most of the prenatal exposure to alcohol and substance use reported on the Helpline occurs inadvertently. An ongoing study on the use of recreational drugs classified as club drugs (including MDMA, amphetamines, GHB, ketamine, and LSD) in pregnancy found that none of the women enrolled in the study had planned their pregnancies.

Overall Demographics of Callers

The majority of the callers (60%) were inquiring about their own needs as shown in Figure 1. This is not surprising in light of the ease of accessibility, and the safeguard of confidentiality of the Motherisk services. Moreover, because of the negative societal perception regarding the use of alcohol and substance use in pregnancy, women may feel uncomfortable discussing the issue with their own health care providers. Health care professionals, including physicians, pharmacists, nurses, addiction counselors, and midwives, represented 13% of the calls.

FIG. 1 Caller Demographics



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Demographics of Exposed Women

Women of Caucasian descent are more likely to use the Helpline, representing 80% of the callers inquiring about antenatal alcohol and substance use as shown in Table 1. Seventy percent of the women using alcohol and substances were in a stable relationship, either married or in common law status. Statistic Canada indicates that 63% of women giving birth were married, and 24% of women giving birth were single.[56] The marital status differs slightly on this line compared to our general Motherisk line, as more of the callers reported being single. More than half of the women (52%) achieved some level of post secondary education, while a quarter of the callers did not achieve high school. The callers also have a lower Socioeconomic status (SES) than the women who call our general line. This is probably not surprising, however, these women have a higher SES than associated with substance abusers in the general population.

Seventy percent of the women were either employed or self employed, with approximately 22% describing themselves as unemployed, with a small percentage of women who were students on social assistance, or disability. Most of the women (78%) utilizing the Helpline were between 18 and 35 years of age. A small portion of callers inquiring regarding information were under 18 years of age (1%) or more than 40 years of age (4%). The Canadian average age of mothers giving birth was 29.2 years, with women aged 25 to 29 and 30 to 34 sharing the highest birth rates.[56] Motherisk reflects this national trend with 30% of the callers aged 25 to 29, and 28% of the callers aged 30 to 34 years.

TABLE 1 Demographic Factors

Age	<18	18-24.9	25-29.9	30-34.9	35-39.9	>40
	1%	21%	30%	28%	16%	4%
Ethnicity	White	Asian	Aboriginal	Black	Hispanic	Other
	80%	5%	4%	3%	3%	5%
Marital Status	Married	Common-law	Single	Separated		
	46%	25%	27%	2%		
Highest completed education	<Grade 12	High School	University/ College	Professional Degree		
	25%	23%	47%	5%		
Employment Status	Employed	Self Employed	Unemployed	Student	Social Assistance	Disability
	65%	3%	22%	6%	2%	2%

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Types of Exposures

More than half of calls involved exposure to alcohol, with 27% of all inquiries made on alcohol alone. A higher percentage of women reported combining alcohol with other substances compared to consuming alcohol alone. The callers most commonly combined alcohol with cigarette, or marijuana, or cocaine. Among the 17,318 calls received, 22 % of the calls pertained to exposure to one single substance. Only one tenth of all inquiries involved exposures to two or more substances without the combination of alcohol. The five most common types of exposures to the Motherisk alcohol and substance use Helpline were regarding exposures to alcohol, nicotine, marijuana, crack/cocaine and opioids in descending order (*see* Figure 2). The three most commonly used recreational drugs were analyzed further to observe its individual yearly trend over the last ten years (*see* Figure 3). Nicotine and marijuana exposures reported by the callers have been stable over the last 10 years. However, the number of inquiries involving cocaine exposures in pregnancy and lactation has been steadily increasing since 1998.

FIG. 2

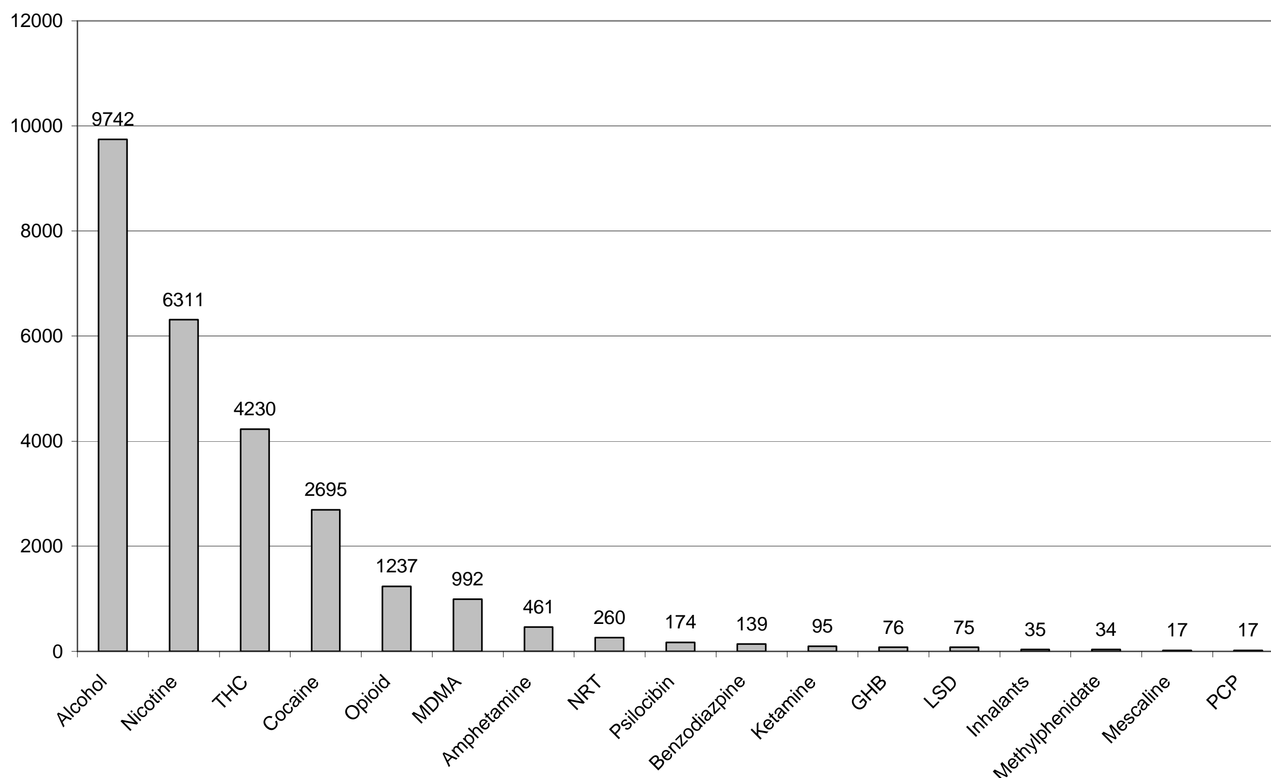

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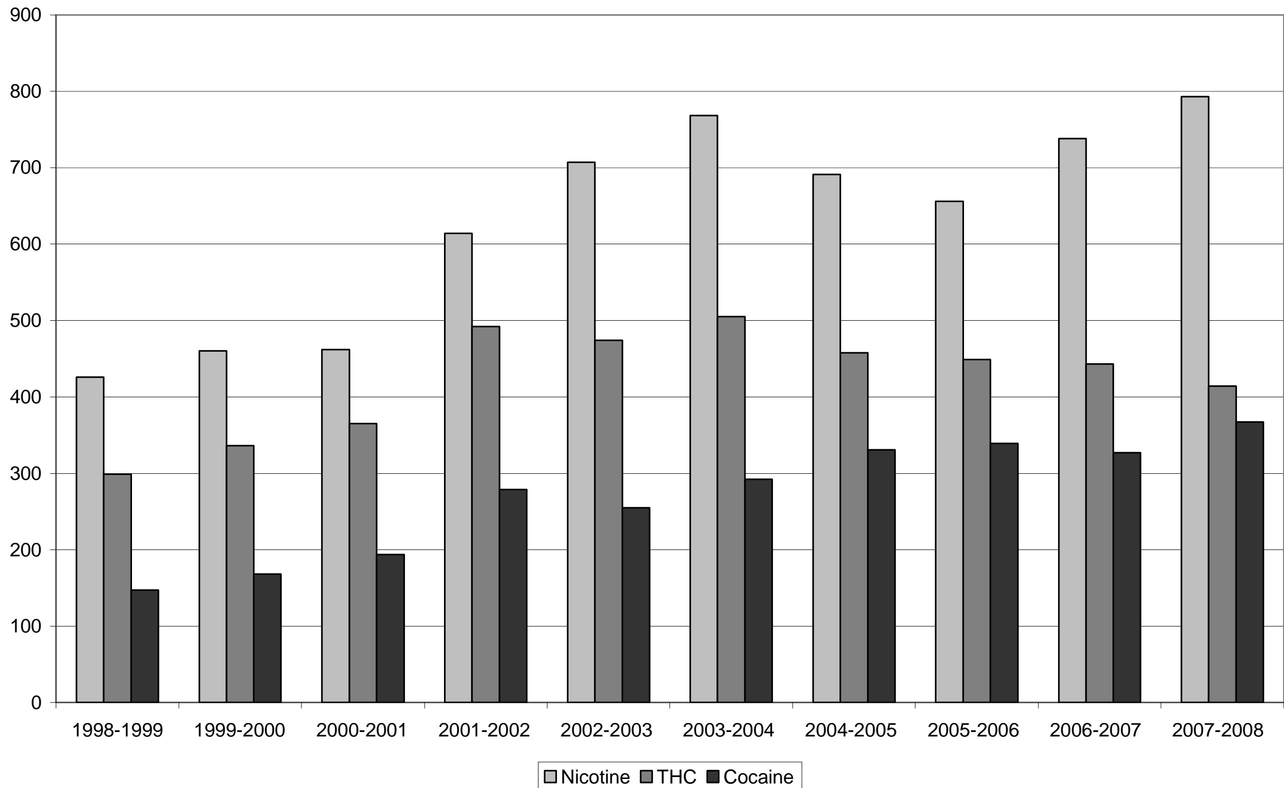
FIG. 3



DISCUSSION

Despite our best attempts to reach high risk women using substances in pregnancy and lactation, the demographics of our callers over the past decade reveals a selective group of women of which the majority are of Caucasian descent, in stable relationships, employed, with some level of post secondary education. However, studies suggest that women at risk of using substances in the antenatal period are more likely to be of non Caucasian descent, single, unemployed, and with low level of education.[57] The contrast between our callers' demographics and the high-risk population is not surprising as the users of Helpline are typical of the more informed individual. Consequently, it is important to note that this type of high functioning women may be a substance abuser. Stereotyping of individuals more likely to use substances in pregnancy may act as a barrier in the effective identification of pregnant women at risk. Indeed, a discriminatory screening for alcohol and drug use towards women of color, single and of low income has been consistently reported in literature.[59] Therefore, the bulk of pregnant callers reaching the Helpline may represent women missed by their care providers as their demographical characteristics deviate from the stereotyped group of women with substance use in pregnancy.

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Despite the contrasting demographics of the Motherisk callers and high risk group of women, their reported exposures reflect the national trends. Nicotine use during pregnancy has been relatively stable over the years as described by other researches.[60] (*see* Figure 3). The Centre for Mental Health and Addiction (CAMH) reported a slight increase in the use of cannabis from 9% in 1997 to 13% in 2003 and since 2003, their data indicate that marijuana use has been stable.[60] Inquiries regarding exposures to marijuana on the Motherisk Helpline reflect this stable trend over its first 10 years of service. The percentage of women using cocaine in Canada between the years 1997-2003 has also been reported to be stable overall. However, when analyzed by age group, the report noted a drastic increase in young population aging between 20-29 years of age.[60] On the Motherisk Helpline, cocaine use has been steadily increasing since 1998, which may result from the majority of our callers being in this specific age group.

The Helpline requires the initiation of the caller - and to date only a small percentage of women with heavy alcohol and substance use appear to utilize our service. In an attempt to reach out to those who are most vulnerable, Motherisk is working in partnership with other organizations such as *Breaking the Cycle*, a community program in downtown Toronto, where alcohol and drug dependent mothers are offered a comprehensive range of services, including parenting and early childhood intervention programs.[61]

Although the present data indicate that Motherisk Helpline has access to a selective group of women, primary health care workers have the opportunity to be in contact with individuals across all social and ethnic barriers, including problem alcohol and substance using women as part of their prenatal care. Training primary care workers on approaches and methods of counseling women on substance use may result in reduced prevalence of alcohol and substance use in pregnant women. Indeed, a short training on the use of substances in pregnant women has been shown to provide confidence and empathy of health care workers[62], both of which are important factors in the treatment of women's addiction problems during pregnancy.

Our experience in running this helpline for more than 10 years further emphasizes the importance for a non-judgmental approach in discussing risks associated with antenatal exposure to alcohol and substances. Punitive and confrontational attitudes may drive these women away from health and prenatal care, further keeping them away from seeking the help they need. Women with alcohol and substance use issues may commonly find themselves in a complex situation[62] with many of them having experienced abuse and trauma, for which substance use became a method of coping.[39,40] In addition, women with alcohol and substance use problems are more likely to suffer from untreated mental illnesses, such as anxiety and depression.[41-43]

However, it is very important to recognize that most women are motivated to reduce or quit their alcohol and substance use during their pregnancies. Therefore, to better prepare the health care workers in the complex issues of substance use in pregnancy, a national consensus and guidelines needs to be developed.

Future Directions

Several aspects of the Helpline could be improved to provide more efficient and accurate information. Despite this being a Canada wide toll free line, providing information in both French and English, the geographical distribution of calls received indicates a large disparity. To reach Canadian women outside Ontario who may require this type of assistance, we need a more effective promotion of the helpline in all Canadian provinces. We can do this by building a stronger network with programs in these communities by providing information about our helpline, educational materials and workshops in these communities. We will continue to strive to conduct rigorous research on the topic of alcohol and substance use in pregnancy, to enable us to disseminate evidence-based information to women who need it. We will also continue to collaborate with services throughout the country that provide substance abuse treatment, so women can receive the help they need in their own environment.

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Acknowlegement
The Motherisk Alcohol and Substance Use Helpline is supported by the Brewers Association of Canada.

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