University of Alberta

Diabetes in Pregnancy among First Nations Women in Alberta: A Multiphase Mixed Methods Approach

by

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Dedication

For Celia and Duncan. Stand, and be true.

Abstract

Background

Diabetes in pregnancy is thought to be an important driver of the current epidemic of type 2 diabetes in First Nations populations.

Purpose

The purpose of this doctoral research was 1) to generate an epidemiological profile of First Nations diabetes in pregnancy in Alberta; and 2) to qualitatively explore among First Nations women both the experience of having diabetes in pregnancy and the factors that contribute to achieving a healthy pregnancy.

Methods

De-identified provincial administrative data of delivery records was obtained for the years 2000-2009. Pregestational, past obstetrical, and delivery outcomes and problems were described and compared by ethnicity and diabetes status. Rates of gestational diabetes mellitus (GDM) and pregestational diabetes were compared by ethnicity, as were longitudinal changes over time. Diabetes in pregnancy predictors were explored via logistic regression. A focused ethnography was conducted with 12 First Nations women with previous diabetes in pregnancy who sought care in Edmonton. Unstructured interviews were carried out and were recorded, transcribed, and subject to qualitative content analysis.

Results

Quantitative: First Nations women were more likely to have antenatal risk factors and adverse infant outcomes, which were compounded by diabetes. Although GDM rates were higher among First Nations women, prevalence grew more

rapidly over time in non-First Nations women. The longitudinal rates of pregestational diabetes were generally steady, yet First Nations women endure a greater than two-fold higher prevalence. Being of First Nations descent was an independent predictor of diabetes in pregnancy.

Qualitative: The experience of diabetes in pregnancy is one wrought with difficulties but balanced to some degree by positive lifestyle changes. A struggle for control permeated the pregnancy experience, but having a strong support system (family, healthcare, cultural/community and internal) and the necessary resources (primarily awareness/education) allowed women to take some control of their health.

Conclusions

As high-risk pregnancies and poor outcomes are more common among First Nations women regardless of diabetes status, efforts must be made to improve pregnancy care. Specifically, these efforts should strive to enhance the support systems of these women, increase their sense of autonomy, and raise awareness of diabetes in pregnancy and its accompanying challenges.

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List of Abbreviations

AAPC - Average Annual Percent Change

ADA - American Diabetes Association

AHW - Alberta Health & Wellness

ANOVA - Analysis of variance

APHP - Alberta Perinatal Health Program

BMI - Body mass index

CDA - Canadian Diabetes Association

CI - Confidence interval

GDM - Gestational diabetes mellitus

IADPSG - International Association of Diabetes and Pregnancy Study Groups

LGA - Large for gestational age

NICU - Neonatal intensive care unit

OGC - Oral glucose challenge

OGTT - Oral glucose tolerance test

OR - Odds ratio

PIH - Pregnancy induced hypertension

RHS - Regional Health Survey

SD - Standard deviation

SGA - Small for gestational age

CHAPTER 1

Introduction

1.1 Purpose

A worldwide increase in type 2 diabetes prevalence is occurring seemingly unabated (1). It is believed that a complex combination of social, cultural, environmental and genetic factors have led to Canadian First Nations populations suffering type 2 diabetes rates that are reportedly 2-5 times higher than the non-First Nations population (2, 3), with First Nations women being excessively affected (4-6). In attempts to understand the causes of this epidemic, the possible contribution of diabetes in pregnancy, particularly gestational diabetes mellitus (GDM), has received recent attention. In First Nations populations, it is suggested that diabetes in pregnancy contributes to a vicious cycle by increasing the risk of type 2 diabetes in both offspring and mothers (4, 7-11). Driving this cycle is increasing obesity prevalence in the younger age groups, coupled with a decrease in the average age of diabetes diagnosis among First Nations individuals (4, 5, 12). Moreover, fertility/birth rates are 1.5-2 times that of the non-First Nations population (13). Hence, pregnancy may be a crucial point for interventions and appropriate healthcare aimed at ultimately reducing type 2 diabetes rates in First Nations peoples.

This thesis covers the initial two studies of an overall multiphase mixed methods plan to examine diabetes in pregnancy among First Nations women in Alberta, Canada. I used administrative data to explore diabetes in pregnancy epidemiology and qualitative data to understand the context of diabetes in pregnancy in First Nations women.

1.2 Research Objectives

The impact of diabetes in pregnancy in First Nations populations is a new and expanding area of research, and many questions remain unanswered. The objectives of this thesis research were two-fold:

1) To use administrative data from the Alberta Perinatal Health Program (APHP) and the Ministry of Alberta Health & Wellness (AHW) to generate an epidemiological profile of First Nations diabetes in pregnancy in Alberta; and

2) To use a focused ethnographic approach to understand the experience of diabetes in pregnancy and what factors could contribute to achieving a healthy pregnancy in First Nations women.

1.3 Background

1.3.1 First Nations Peoples and the Epidemic of Type 2 Diabetes

Second only to New Zealand, the Aboriginal peoples' (constitutionally recognized as First Nations, Métis, and Inuit) share of the Canadian population is high at 3.8% (13). Approximately 700,000 First Nations individuals live in Canada, comprising roughly 2.2% of the total population. The majority of First Nations live in Ontario (23%), British Columbia (19%), Manitoba (14%), Alberta (14%) and Saskatchewan (13%; 13). According to the 2006 census, roughly 97,275 First Nations live in Alberta, 54% of whom reside on-reserve within the 46 First Nations bands (13).

The term First Nations encompasses a vast diversity of cultural and linguistic groups. There are more than 600 recognized separate First Nations bands across Canada, and 12 First Nations language groups comprised of more than 50 different languages (14). Alberta's First Nations population is mostly made up of Blackfoot, Cree, Dene/Chipewyan and Dakota/Sioux peoples (13, 15). First Nations communities are often distinct in many ways, including culture, history, socio-political and socio-economic factors (14).

On the whole, the First Nations population of today is young, growing and urbanizing. Statistics Canada estimated the median age of First Nations peoples was 25 years in the year 2006, whereas that of the general Canadian population was 40 years of age (13). Moreover, one third of the First Nations population is under the age of 15. Over a ten year span from 1996 to 2006, the First Nations population grew by 29%, 3.5 times than that of their non-First Nations counterparts. Also in 2006, approximately 50% of First Nations individuals lived in urban areas (13). Still, the majority (80%) of those in rural areas are living on First Nations reserves. According to Health Canada, approximately 22% of reserves are in remote locations with no road access (16).

Many Indigenous peoples around the globe are being threatened by significant increases in type 2 diabetes incidence and prevalence, in spite of their diverse experiences, identities, histories and genetic backgrounds (17). These same Indigenous populations often share a common past of systemic oppression, marginalization and disempowerment (3). This is indeed the case for First Nations peoples, who have experienced a profound epidemiological shift in their health

status. The starvation, wars and infectious diseases that accompanied colonization resulted in dramatic depopulation, which has recently given way to both re-population and a rise in chronic diseases such as obesity, type 2 diabetes and cardiovascular disease (18).

Today, the prevalence of type 2 diabetes is at least twice as high for the overall First Nations population compared to the general population (2), yet prior to the 1950s type 2 diabetes was unheard of in First Nations peoples (19). Current prevalence estimates vary depending on the methodology utilized and the specific population being studied, but likely all of these statistics are underestimated due to high rates of undiagnosed type 2 diabetes observed in First Nations populations (20, 21). National age-standardized estimates from the First Nations Regional Health Survey (RHS) show a self-reported diabetes prevalence rate of 20.7% among adult First Nations respondents (22). By comparison, only 6.4% of the total population over the age of 12 self-reported having diabetes in the 2010 Canadian Community Health Survey (23). In Alberta, analysis of administrative databases revealed an age- and sex-standardized diabetes prevalence of 13.5% for First Nations adults, compared to only 6.0% for the general population for the year 2007 (5). Other administrative studies in Canada substantiate these ethnic differences, yet the differences in Alberta and British Columbia are lower than those for Manitoba and Saskatchewan (4, 5, 24, 25). Furthermore, the rise in diabetes prevalence and incidence was less pronounced among the First Nations population in Alberta than that of the general population over a 13 year time span (5). That being said, among the First Nations population the epidemic of

childhood obesity has yet to peak (26), rates of GDM are also higher in comparison to the general population (7), and youth-onset type 2 diabetes and pre-diabetes are increasingly being identified (27- 29), all of which may lead to a surge of type 2 diabetes in the future.

First Nations females tend to have higher diabetes prevalence rates compared to males, which is opposite to the general Canadian population where rates are even amongst both sexes, or even slightly higher for males (4, 5). However, the sex-specific gap in diabetes among First Nations may be diminishing as males experienced an accelerated rise in diabetes prevalence and incidence compared to females between 1995-2007 in Alberta (5). Similarly, diabetes prevalence has increased to a greater extent among First Nations boys compared to girls over the same time period (29).

Type 2 diabetes is affecting First Nations populations at a younger age than the Canadian population at large. In Saskatchewan, the number of incident cases is highest among First Nations adults aged 40-49, while most new diabetes cases among the general population were in those greater than 70 years of age (4). Also, as indicated by the initial RHS report, the majority (53%) of those with diabetes in First Nations communities were less than 40 years of age (30). Furthermore, Dean and colleagues (31) showed crude type 2 diabetes incidence has increased among First Nations youth (ages 0-19) to 0.55/1000 in 2001 (no baseline was reported). Similarly, among Albertan youth, the prevalence of diabetes was higher in the general population compared to the First Nations population in 1995, but by 2007 there were no between group differences, as the

Average Annual Percent Change (AAPC) in prevalence over time was significantly higher for First Nations vs. general population youth (6.98 AAPC vs. 3.93 AAPC respectively; 29).

First Nations individuals with type 2 diabetes experience complications such as retinopathy, end-stage renal disease, neuropathy, foot disorders, and cardiovascular disease more frequently than other groups (32-36). In the recent RHS, 66.1%, 29.1% and 10.5% of respondents with diabetes (ages 55 and older) reported having hypertension, heart disease, and stroke versus 40.7%, 15.2%, and 4.9% for those without diabetes, respectively (22). In Alberta, this increased burden of diabetes is also supported by reports of higher numbers of diabetes-related emergency department and general practitioner visits, as well as longer hospital stays due to diabetes among First Nations compared to non-First Nations (37). Moreover, all-cause mortality rate among First Nations with diabetes is 1.6 times higher than that of the general population with the disease in Alberta (5). Similarly, administrative data in British Columbia found First Nations males and females with type 2 diabetes were 1.5 and 2.2 times more likely to die compared to the general population with type 2 diabetes, respectively (38).

There is a great deal of literature describing the epidemiology of type 2 diabetes among First Nations populations. However, it is important to make note of the limitations of generalizing all First Nations peoples, although this is done frequently for simplicity. Results of community-specific diabetes projects, such as those in the remote First Nations communities of Sandy Lake, Ontario (20), Wapekeka and Kasabonika, Ontario (39), as well as the Eeyou Istchee community

of northern Quebec (35), show that diabetes prevalence likely varies among individual First Nations communities. Comparison studies aimed at elucidating differences, and reasons for differences, are limited.

The causes of type 2 diabetes in the First Nations population are multifaceted. Briefly, the inequalities in the social determinants of health as well as the socio-cultural disruption brought about through contact with Europeans are thought to be the root cause (2, 40, 41). First Nations peoples have been subject to various cultural disturbances including the decimation of traditional lifestyles, forced sedentarization, loss of language, disempowerment, political marginalization, systemic racism, relocation/confinement to reserves and the loss of land (and connection to the land), as well as emotional, spiritual and mental disconnection (41). Subsequently, First Nations peoples have lower completion rates of all levels of education, higher unemployment rates, lower incomes, poorer access to health services, more crowded living conditions, and less social support than the general Canadian population (40). These social and cultural inequities likely underlie the main risk factors for type 2 diabetes which apply to First Nations peoples: stress, dietary acculturation to an unhealthy diet, food insecurity, physical inactivity, obesity, and high rates of diabetes in pregnancy (2). Finally, there is a strong genetic component to type 2 diabetes, and genetic variants and the thrifty gene theory may explain in-part the rise of type 2 diabetes in First Nations populations (42), however evidence of such is extremely limited. The focus of this thesis however, is to examine a specific touted cause: diabetes in pregnancy.

1.3.2 Diabetes in Pregnancy

Diabetes in pregnancy can come about one of two ways: GDM or pregestational diabetes with a subsequent pregnancy. The former is more common, as GDM accounts for up to 90% of diabetes cases during pregnancy (43), and is certainly more studied. GDM is defined by glucose intolerance with onset or first recognition during pregnancy (44). GDM is one of the most common medical complications of pregnancy (45), and accordingly, all pregnant women in Canada are recommended by the Canadian Diabetes Association (CDA) to be screened between the 24^{th} and 28^{th} week of pregnancy (44).

Although most organizations utilize the gold standard oral glucose tolerance test (OGTT) for the diagnosis of GDM there is no global consensus on the diagnostic criteria, which is currently being debated (46). In Canada, it is recommended that all pregnant women be screened by an initial 50g oral glucose challenge (OGC) and subsequent blood glucose measurement at one hour post-consumption (44). A one hour post-OGC result of 11.1 mmol/L or greater is GDM. An OGC value between 7.8-11.0 mmol/L is considered 'abnormal,' and necessitates further testing for the potential diagnosis of GDM. If two of the following subsequent results are found then GDM is confirmed: fasting glucose 5.3 mmol/L or higher, one hour post-OGTT (75g glucose) result of 10.6 mmol/L or higher, or a two hour post-OGTT (75g glucose) result of 9.0 mmol/L or higher (44). Based primarily on results of the Hyperglycemia and Adverse Pregnancy Outcomes study which showed an association between maternal glucose levels below those for the diagnosis of diabetes (i.e. fasting glucose less than 5.8

mmol/L or a two hour post OGTT less than 11.1 mmol/L) and increased birth weight (47), both the International Association of Diabetes and Pregnancy Study Groups (IADPSG) and the American Diabetes Association (ADA) endorsed new lower diagnostic criteria for GDM (45, 48). Under these new criteria, women at 24-28 weeks gestation with values greater than 5.1 mmol/L (fasting), 10.0 mmol/L (one hour post OGTT) or 8.5 mmol/L (two hour post OGTT) would be classified as GDM (44). The CDA guidelines state that the method for GDM screening used by the IADPSG and the ADA can be used as and "alternative approach" (44).

Pregestational diabetes in pregnancy can come about from either type 1 diabetes or type 2 diabetes. A diagnosis of type 1 diabetes or type 2 diabetes is made by either a fasting glucose ≥ 7.0 mmol/L, a random glucose ≥11.1 mmol/L, a two hour post OGTT ≥11.1 mmol/L, or a hemoglobin A1C value ≥ 6.5% (in adults; 44). When patients are asymptomatic, if a single test result is in the diabetic range then a repeat confirmatory test must be done (44). Sometimes pregestational diabetes goes undiagnosed until pregnancy and could be misclassified as GDM. The IADPSG calls this 'overt' diabetes in pregnancy (45).

The majority of the antepartum risks of diabetes in pregnancy are to the infant, who is at greater risk for many conditions, including stillbirth, congenital abnormalities, hypoglycemia, hypocalcemia, jaundice, macrosomia, birth trauma (such as shoulder dystocia), prematurity, respiratory distress syndrome and others (46, 49, 50). Infants with congenital abnormalities born to mothers with GDM are often assumed to be the consequence of undiagnosed maternal type 2 diabetes

(overt; 51), and it is not clear whether GDM alone causes malformations (52). Mothers with diabetes in pregnancy have an increased risk of preeclampsia, cesarean section and preterm delivery (53). Although the condition generally disappears after birth, GDM is one of the strongest identifiable predictors for type 2 diabetes in women (54). GDM also carries an increased risk of recurrent GDM in future pregnancies, as well as maternal hypertension and cardiovascular disease postnatally (55-58). As for the infant, it is well documented that offspring of women with diabetes in pregnancy have a heightened risk of developing obesity and type 2 diabetes in their lifetime, independent of genetic risk and other risk factors (46, 59, 60). Children are also at risk for adverse neurological, psychomotor and psychosocial outcomes (61-64).

Considering the risks, diabetes in pregnancy management aimed at normalizing blood glucose concentrations is imperative. Treatment has been shown to significantly reduce the risk of macrosomia, being large for gestational age (LGA), shoulder dystocia, nerve palsy, metabolic complications and respiratory complications among neonates (51, 65, 66). Management of GDM can also reduce maternal hypertensive disorders during pregnancy (67). Treatment ideally involves pregestational planning in the client with type 1 diabetes or type 2 diabetes to achieve the best possible control preconception (68). Pregestational diabetes in pregnancy requires rigorous dietary counseling, strict metabolic monitoring (self-monitoring of blood glucose) and insulin. Diabetes in GDM patients can sometimes be controlled with diet, lifestyle and monitoring alone but many (up to 50% in some populations) eventually require insulin therapy (65).

The use of the oral glucose-lowering agents, particularly metformin and glyburide, is suggested in GDM by the International Diabetes Federation as an alternative when glycemic goals have not been reached by dietary means, although the safety of these drugs has not been systematically investigated (69, 70).

For mild GDM, in parallel with the debate about diagnostic criteria, the need for treatment is not fully agreed upon. Long-term outcomes such as childhood obesity and maternal type 2 diabetes development have not been shown to be altered by GDM treatment during pregnancy (70, 71). In addition, there is debate over concerns that strict GDM treatment may cause undue maternal stress, increase the risk of small for gestational age (SGA) neonates, and provoke subsequent adverse metabolic outcomes in infants (45, 72-75). As an example, although mild exercise may improve metabolic control and reduce the risk of delivering a macrosomic infant (76, 77), controversy exists surrounding the fetal wellbeing resulting from more vigorous exercise, particularly in women with (or at risk for) preeclampsia (70).

The exact cause of GDM is unknown (73). The normal progression of pregnancy alters glucose metabolism, and is often considered a state of mild insulin resistance or glucose intolerance (73). Through a complex interaction of hormonal and physiological changes that are not fully understood, insulin sensitivity begins to decrease in the second trimester, leading to a slight increase in postprandial blood glucose, which is thought to be necessary for the rapidly growing and developing fetus (73). The vast majority of pregnant women do not develop GDM however, as compensatory increases in insulin production and

secretion overcome insulin resistance (46). Pregestational overweight and obesity, elevated glucose concentrations in the first trimester (in women without known diabetes), increased maternal age, previous GDM or delivery of a macrosomic baby, family history of diabetes, maternal low or high birth weight (LBW; HBW), hypertension, history of polycystic ovary syndrome, and low socio-economic status are known risk factors (7, 73, 78, 79).

Globally, GDM affects approximately 1-14% of pregnancies, varying in direct proportion to the population prevalence of type 2 diabetes (80, 81). Population differences in age, ethnicity and diagnostic methods also contribute to the diversity in rates (82, 83). Large population-based studies in the United States have shown the incidence of GDM increased from 5% in 1991 to 7.1% in 2000, independent of ethnicity or age (83, 84). In Canada there is no national registry data for GDM specifically. However, the 1994-1995 National Longitudinal Survey of Children and Youth found that 6.5% of women who had children under the age of two reported "pregnancy diabetes" in their most recent pregnancy (85). The APHP collects longitudinal provincial data on a number of indicators related to perinatal health and mortality, including GDM. For the entire Alberta population (ethnicity was not explored), annual rates of GDM rose from 3.2% in 2000 to 3.9% in 2006 among women who gave birth (86).[1]

Pregestational diabetes in pregnancy is less common than GDM. In Alberta, the APHP has longitudinal data on pregestational diabetes in pregnancy for the province as a whole, showing stable rates of 0.7% of pregnancies over

[1] More recent data (unpublished) from APHP suggests the rate of GDM in 2008 in Alberta to have risen to 4.5% of all pregnancies.

time (86). Conversely, epidemiological studies in other populations in the United States, Europe and Australia show incidence rates of pregestational diabetes in pregnancy are rising due to increases in type 2 diabetes during pregnancy (87-90). These studies indicate that the incidence of type 2 diabetes during pregnancy is overtaking that of type 1 diabetes (87-90). Similarly, type 2 diabetes, which was originally thought to pose less of a hazard during pregnancy, confers a greater risk for adverse outcomes (congenital malformations and perinatal mortality in particular) than type 1 diabetes according to recent studies (44, 90). In Canada, more research is needed regarding the epidemiology of pregestational diabetes in pregnancy.

1.3.3 Diabetes in Pregnancy among First Nations Women

It has been suggested that many of the traditional risk factors for GDM may be magnified in First Nations women, and First Nations descent has been shown to be an independent risk factor for GDM after controlling for pre-gravid overweight, history of GDM, family history of diabetes, age, and rural residence (7, 91). Importantly, socioeconomic status was not controlled for in these studies and First Nations descent may be a proxy marker for low socioeconomic status (40, 41). Conversely though, in a prospective study from first prenatal visit to birth in Alberta, Wenman et al (92) found no relationship between Aboriginal status and macrosomia. The Aboriginal sample size (n = 70) was low and thus the Wenman et al study (92) was likely underpowered to detect statistical differences.

A number of studies suggest that First Nations women have higher rates of GDM than non-First Nations. Harris et al (93) and Willows et al (94) both

conducted retrospective analyses among Ojibway-Cree women from northwestern Ontario and Cree women in Quebec respectively, finding 8.4% and 10.3% had GDM. In two separate studies among James Bay Cree women, one among a single community in Ontario and the other among nine communities in Quebec, GDM was diagnosed in 12.8% and 8.5% of women respectively (8, 10). Dyck et al (7) found GDM rates were significantly higher among First Nations women (6.4%) compared to non-First Nations women (3.5%) in urban Saskatoon, Saskatchewan. In the 2002/2003 national First Nations RHS, 11.9% of adult First Nations women reported ever having GDM (6). Aljohani et al (91) utilized administrative prenatal information to report GDM rates over a 20 year period in Manitoba. The authors found First Nations women had GDM rates that were 3 times higher than their non-First Nations counterparts (91). Notably, age-adjustments have not been conducted on GDM rates when comparing First Nations and non-First Nations. Since advancing maternal age is a risk factor for GDM (73), and the Canadian Aboriginal population is predominantly young (13), one could speculate that rates of GDM among First Nations women may have been underestimated in previous studies. Although unadjusted rates contribute valuable information, age-adjustment may be better to analyze for etiological clues. Thus, age-adjusted rates of GDM by First Nations ethnicity are needed. Additionally, at present there is little longitudinal data on rates of diabetes in pregnancy in First Nations women.

Research among the Pima Indians (95) of the United States and Australian Aborigines (96) suggest that Indigenous women with diabetes in pregnancy are

more likely to experience adverse pregnancy outcomes. However, few studies have examined delivery or infant outcome data for First Nations women with GDM. In Saskatchewan, Dyck et al (7) have shown Aboriginal women with GDM were more likely to have hypertension or previous cesarean section than Aboriginal women without GDM. Aboriginal infants of GDM mothers were more likely to be macrosomic and hypoglycemic than those of non-GDM mothers, although mean gestational age, mean birth weight, and the proportion of those LGA, SGA, with LBW, and with any congenital anomalies did not differ between groups (7). Dyck et al (7) also found Aboriginal identity was a predictor of GDM, and among Aboriginal women specifically age $\geq$ 33 and pregravid body mass index (BMI) $\geq$ 27 were predictors. However, the possible contribution of other antenatal factors (e.g. previous hypertension, renal disease, neonatal death, abortion, cesarean section, major fetal anomaly, maternal anemia, smoking status, alcohol and substance abuse) to predict diabetes in pregnancy or pregnancy outcomes in Aboriginal women has remained unexplored.

In James Bay Cree women in Ontario, GDM was associated with macrosomia, hyperbilirubinemia, hypoglycemia and hypocalcemia (10). Recently, First Nations women with diabetes in Ontario were shown to have higher rates than non-First Nations women with diabetes of preterm delivery, and to have babies with HBW, jaundice, hypoglycemia and shoulder dystocia (97). Other important outcomes were not explored however, including breast feeding occurrence, major fetal anomaly, abortion, APGAR score, stillbirth occurrence, neonatal death, and indications for induction. Moreover, Liu et al (97) were

unable to adjust for other risk factors and confounding factors, most notably age. Although not focusing on diabetes in pregnancy, Shah et al (98) recently conducted a systematic review and meta-analysis on pregnancy and neonatal outcomes in Aboriginal women, indicating an elevated risk of adverse outcomes, particularly preterm birth. The authors stressed that future studies assessing confounder adjusted estimates are needed.

Little is known about the epidemiology of GDM among First Nations women in Alberta. Self-reports of ever having GDM were significantly higher among First Nations women (9.0%) compared to both Métis women (4.5%) and non-Aboriginal women (5.2%) in rural Alberta communities in 2007 (9). From recent analysis of these updated datasets (to January 2012), we have found 9.6% of adult women (mostly Aboriginal) ever reported having GDM (unpublished data). These results are limited however, as women were not from a purposefully representative sample, rather they attended diabetes screening clinics and thus were likely those most concerned about their health.

Only one study has explored rates of pregestational diabetes in pregnancy among First Nations women. Liu et al (97) showed higher rates in First Nations women (3.9%) compared to non-First Nations women (1.8%) in a large cross-sectional retrospective population-based cohort in Ontario. However, outcomes and risk/confounding factors of such pregnancies have yet to be studied, and rates over time have not been reported. Such information is needed, as pregnancies complicated by pregestational diabetes not only carry all the same risks as GDM, but are associated with higher risks of adverse perinatal outcomes (including

congenital abnormalities) than those complicated by GDM in non-Aboriginal populations (46, 49, 50). Research suggests that the age of onset of type 2 diabetes in First Nations population is decreasing (4, 5, 12), which may be reflected by increasing pregestational diabetes and will further impact pregnancy outcomes. Moreover, recent evidence suggests type 2 diabetes is a higher risk condition during pregnancy compared to type 1 diabetes (44, 90), and is much more common among First Nations populations than type 1 diabetes (2).

1.3.4 Diabetes in Pregnancy and Type 2 Diabetes

Diabetes in pregnancy predisposes both women and their offspring to future type 2 diabetes (54, 59, 60). Increasingly diabetes in pregnancy is being denoted as a key intra- and inter-generational perpetuator to the growing diabetes epidemic (60, 99).

Women with GDM have, on average, a 7-fold increased risk of developing future type 2 diabetes compared to women whom had normo-glycemic pregnancies (43). In a large Canadian population-based study, Feig et al (100) found the probability of having diabetes at nine years post-delivery was 18.9% for women that had GDM and 2.0% for those without GDM. Moreover, it has been suggested that up to one third of women whom currently have diabetes may have previously had GDM (54). The reasons for subsequent increased risk are not fully understood but may include elevated pancreatic stress and reduced function of the insulin producing beta-cells of the pancreas, which in turn predisposes women to type 2 diabetes (73). The risk of diabetes varies depending on the population being studied and is further elevated among obese women and those with a family

history of diabetes (46, 101), which is particularly problematic for First Nations women who suffer significantly high rates of both diabetes and obesity (9, 102). For instance, a retrospective chart review of First Nations women diagnosed with GDM in the Sioux Lookout Zone, Ontario found that greater than 70% developed type 2 diabetes within four years (103).

It is also clear that infants born to mothers that had GDM are much more likely to develop type 2 diabetes, independent of other risk factors for diabetes such as low socio-economic status, physical inactivity, over-nutrition, obesity, and stress (46, 59, 60). Intrauterine programming, fetal origins of adult disease, and epigenetics are currently major areas of research activity. Among the Pima Indians, type 2 diabetes and obesity were more prevalent among siblings born to the same mother after she developed diabetes (104). Pima offspring of mothers with diabetes in pregnancy have also been shown to develop diabetes at an earlier age than offspring of mothers without diabetes (104-106), a finding that has been confirmed in other populations in the SEARCH for Diabetes in Youth Study (107). Building from the original Barker hypothesis (108, 109), as well as animal and epidemiological data, it is believed that the physiologic environment of over-nutrition experienced in the womb of women with diabetes in pregnancy 'programs' offspring to a life of subsequent over-nutrition, insulin resistance, and in all likelihood, eventual type 2 diabetes (110). For First Nations, the theory has been taken even further with the coining of the "hefty fetal phenotype" hypothesis (111). The premise of this hypothesis is that an early survival mechanism developed in First Nations women in order to generate well nourished infants in

the womb, which has become a contemporary liability that now predisposes such infants to type 2 diabetes (111). Recently, population-level simulation modeling suggests that GDM may be responsible for 19%-30% of all type 2 diabetes cases in Saskatchewan First Nations compared to only 6% in the non-First Nations population (112). Also, Mendelson et al (113) found extremely high rates of diabetes among offspring of Oji-Cree mothers that have pediatric onset type 2 diabetes: 25% among offspring aged 7-19 and 43% among offspring aged 10-19.

1.4 Rationale

Many of the authors quoted above are unified in their urgent call for programs/interventions to prevent GDM and optimize the management of diabetic pregnancies in the First Nations population (4, 7-10, 91, 93), yet a description of what type of programs are needed or are in place is not readily found in the literature. Although specific GDM treatment (e.g. diet, monitoring, and insulin if necessary) described by Alwan et al (114) among women decreases infant morbidity, physical activity interventions over and above this care have not been successful in further improving pregnancy outcomes (115). Results of lifestyle interventions to prevent GDM including a recent systematic review of nutritional therapies have been modest at best (116-118). Among Canadian First Nations women specifically, interventions have only taken the form of lifestyle change (diet and exercise), which have been unsuccessful in GDM prevention (119-121). This is not surprising since the lifestyle changes required for prevention and management of both GDM and type 2 diabetes are highly dependent on the social

determinants of health which lie beneath the increase in contemporary risk factors for diabetes described previously (2, 3, 40). For Aboriginal women, cultural destruction resulting from colonialism has led a myriad of interconnected problems which may be at play, including lower education completion rates, poorer social support, higher prevalence of substance abuse, higher unemployment rates, lower incomes, higher rates of infectious diseases and mental illness, more crowded living conditions, loss of traditional language, higher rates of violence and abuse, disempowerment, marginalization, racism, loss of land, in addition to emotional, spiritual and mental disconnection (3, 40, 41, 122, 123). Dealing with such conditions may preclude appropriate GDM management or prevention in most First Nations women. In fact, Dyck et al (7) have shown that Aboriginal women are screened for GDM at significantly lower rates compared to general population women (68.5% and 83.0% respectively). Also, Liu et al (97) found 64.4% of First Nations women with diabetes received antenatal obstetric care compared to 94.9% for non-First Nations women with diabetes in Ontario. Qualitative research has also suggested that many First Nations individuals do not seek care from the mainstream system for a variety of reasons that are generally culturally based (124, 125). Additionally, current models of health practice have yet to acknowledge the influence on First Nations health of colonialism-based historical and social contexts, or ethno-cultural affiliation (124, 126, 127). Hence, a lack of cultural sensitivity on the part of healthcare professionals, as well as a lack of understanding of and familiarity with the biomedical system on the part of First Nations individuals may be deterrents

to proper GDM care (128). Furthermore, many First Nations women may have inadequate access to appropriate healthcare services, particularly in rural/remote settings (129). These challenges require novel approaches.

Previous prevention interventions have not taken into account the cultural differences of First Nations women, nor the psycho-social context in which diabetes in pregnancy is occurring in these women, which may be necessary for treatment and prevention improvements (124, 126, 127, 130, 131). Qualitative insights into the experiences of other non-Aboriginal populations of women with GDM have been recently explored however (131-135). For novel strategies to improve diabetes in pregnancy outcomes (and ultimately reduce the burden of type 2 diabetes) to be developed, the cultural, physical and social milieu in which these individuals live must first be well understood. Thus, an investigation into diabetes in pregnancy epidemiology, as well as the experiences, awareness, access to care, and needs of women, is warranted among the First Nations population in Alberta. Such an investigation will also help address identified research gaps, namely in the longitudinal epidemiology of GDM and pregestational diabetes in pregnancy, as well as outcomes and risk/confounding factors of such pregnancies.

1.5 Summary

The growth of type 2 diabetes has been exceptionally rapid among Indigenous populations worldwide. The Canadian First Nations population (women in particular) experiences some of the highest rates of type 2 diabetes anywhere. Diabetes in pregnancy (both GDM and pregestational diabetes)

increases the risk for future obesity and type 2 diabetes in the offspring, and is thought to be an important driver of the current diabetes crisis in First Nations populations. Thus, prevention and improved treatment during pregnancy may provide substantial benefit in lessening the burden of type 2 diabetes. Exactly how to achieve this is not known. The extent of the problem has not been well explored, nor addressed. The epidemiology needs to be better characterized, and the cultural, physical and social environment in which these women live has to be considered.

1.6 References

1. Shaw JE, Sicree RA, Zimmet PZ. Global estimates of the prevalence of diabetes for 2010 and 2030. Diabetes Res Clin Pract. 2010;87(1):4-14.

2. Young TK, Reading J, Elias B, O'Neil JD. Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. CMAJ. 2000;163(5):561-6.

3. King M, Smith A, Gracey M. Indigenous health part 2: The underlying causes of the health gap. Lancet. 2009;374(9683):76-85.

4. Dyck R, Osgood N, Lin TH, Gao A, Stang MR. Epidemiology of diabetes mellitus among First Nations and non-First Nations adults. CMAJ. 2010;182(3):249-56.

5. Oster RT, Johnson JA, Hemmelgarn BR, King M, Balko SU, Svenson LW, et al. Recent epidemiologic trends of diabetes mellitus among status Aboriginal adults. CMAJ. 2011;183(12):E803-8.

6. First Nations Centre, National Aboriginal Health Organization. First Nations regional longitudinal health survey (RHS) 2002/03 - Results for adults, youth and children living in First Nations communities. Ottawa, ON: First Nations Centre, National Aboriginal Health Organization; 2005.

7. Dyck R, Klomp H, Tan LK, Turnell RW, Boctor MA. A comparison of rates, risk factors, and outcomes of gestational diabetes between Aboriginal and non-Aboriginal women in the Saskatoon health district. Diabetes Care. 2002;25(3):487-93.

8. Rodrigues S, Robinson E, Gray-Donald K. Prevalence of gestational diabetes mellitus among James Bay Cree women in northern Québec. CMAJ. 1999;160(9):1293-7.

9. Oster RT, Toth EL. Differences in the prevalence of diabetes risk-factors among First Nation, Métis and non-Aboriginal adults attending screening clinics in rural Alberta, Canada. Rural Remote Health. 2009;9(2):1170.

10. Godwin M, Muirhead M, Huynh J, Helt B, Grimmer J. Prevalence of gestational diabetes mellitus among Swampy Cree women in Moose Factory, James Bay. CMAJ. 1999;160(9):1299-302.

11. Willows ND, Hanley AJ, Delormier T. A socioecological framework to understand weight-related issues in Aboriginal children in Canada. Appl Physiol Nutr Metab. 2012;37(1):1-13.

12. Dean HJ, Mundy RL, Moffatt M. Non-insulin-dependent diabetes mellitus in Indian children in Manitoba. CMAJ. 1992;147(1):52-7.

13. Statistics Canada. Aboriginal peoples in Canada in 2006: 2006 census: First Nations people. Ottawa, ON: Statistics Canada; 2006.

14. Applied History Research Group. Canada's First Nations. 2000. Retrieved online [July 2012] at: http://www.ucalgary.ca/applied_history/tutor/firstnations/

15. Government of Alberta. History: First Nations. 2005. Retrieved online [July 2012] at: http://alberta.ca/home/index.cfm?Page=27.

16. Canadian Institute for Health Information. How healthy are rural Canadians? An assessment of their health status and health determinants. Ottawa, ON: Canadian Institute for Health Information; 2006.

17. Yu CH, Zinman B. Type 2 diabetes and impaired glucose tolerance in Aboriginal populations: A global perspective. Diabetes Res Clin Pract. 2007;78(2):159-70.

18. Waldram J. *Aboriginal Health in Canada: Historical, Cultural and Epidemiological Perspectives 2nd Edition*. Waldram J, Herring DA, Young TK. Toronto, ON: University of Toronto Press Incorporated; 2006.

19. Chase LA. The trend of diabetes in Saskatchewan, 1905-1934. CMAJ. 1937;36(4):366-9.

20. Harris SB, Gittelsohn J, Hanley A, Barnie A, Wolever TM, Gao J, et al. The prevalence of NIDDM and associated risk factors in Native Canadians. Diabetes Care. 1997;20(2):185-7.

21. Kaler SN. The BRAID study: Believing we can reduce the Aboriginal incidence of diabetes [dissertation]. Edmonton, AB: University of Alberta; 2005.

22. The First Nations Information Governance Centre. First Nations regional health survey. RHS phase 2 (2008/2010) preliminary results. Ottawa, ON: First Nations Information Governance Centre; 2011.

23. Statistics Canada. Diabetes, 2010. Data from the CCHS. 2010. Retrieved online [February 2013] at: http://www.statcan.gc.ca/pub/82-625-x/2011001/article/11459-eng.htm.

24. Green C, Blanchard JF, Young TK, Griffith J. The epidemiology of diabetes in the Manitoba-registered First Nation population: Current patterns and comparative trends. Diabetes Care. 2003;26(7):1993-8.

25. National Diabetes Surveillance System. Report from the national diabetes surveillance system: Diabetes in Canada. Ottawa, ON: National Diabetes Surveillance System; 2009.

26. Sheilds, M. Overweight and obesity among children and youth. Statistics Canada, Health Reports. 2006;17(3):27-42.

27. Sellers EA, Moore K, Dean HJ. Clinical management of type 2 diabetes in Indigenous youth. Pediatr Clin North Am. 2009;56(6):1441-59.

28. Dabelea D, DeGroat J, Sorrelman C, Glass M, Percy CA, Avery C, et al. Diabetes in Navajo youth: Prevalence, incidence, and clinical characteristics: The SEARCH for diabetes in youth study. Diabetes Care. 2009;32(Suppl 2):S141-7.

29. Oster RT, Johnson JA, Balko SU, Svenson LW, Toth EL. Increasing rates of diabetes amongst status Aboriginal youth in Alberta, Canada. Int J Circumpolar Health. 2012;71(0):1-7.

30. National Steering Committee for the First Nations and Inuit Regional Health Survey. First Nations and Inuit regional health survey. Final report. Ottawa, ON: Health Canada; 1999.

31. Dean HJ, Sellers EA, Young K. Type 2 diabetes in youth in Manitoba, Canada, 1986 to 2002. Can J Diabetes. 2003;27(4):449-54.

32. Hanley AJ, Harris SB, Mamakeesick M, Goodwin K, Fiddler E, Hegele RA, et al. Complications of type 2 diabetes among Aboriginal Canadians: Prevalence and associated risk factors. Diabetes Care. 2005;28(8):2054-7.

33. Oster RT, Virani S, Strong D, Shade S, Toth EL. Diabetes care and health status of First Nations individuals with type 2 diabetes in Alberta. Can Fam Physician. 2009;55(4):386-93.

34. Harris SB, Naqshbandi M, Bhattacharyya O, Hanley AJ, Esler JG, Zinman B et al. Major gaps in diabetes clinical care among Canada's First Nations: Results of the CIRCLE study. Diabetes Res Clin Pract. 2011;92(2):272-9.

35. Dannenbaum D, Kuzmina E, Lejeune P, Torrie J, Gangbe M. Prevalence of diabetes and diabetes-related complications in First Nations communities in northern Quebec (Eeyou Istchee), Canada. Can J Diabetes. 2008;32(1):46-52.

36. Macaulay AC, Montour LT, Adelson N. Prevalence of diabetic and atherosclerotic complications among Mohawk Indians of Kahnawake, PQ. CMAJ. 1988;139(3):221-4.

37. Oster RT, Hemmelgarn BR, Toth EL, King M, Crowshoe L. Chapter 11. Diabetes and the status Aboriginal population in Alberta. In Alberta Diabetes Atlas 2011. Edmonton, AB: Institute of Health Economics; 2011.

38. Jin A, Martin JD, Sarin C. A diabetes mellitus in the First Nations population of British Columbia, Canada. part 1. mortality. Int J Circumpolar Health. 2002;61(3):251-3.

39. Imbeault P, Haman F, Blais JM, Pal S, Seabert T, Krummel EM, et al. Obesity and type 2 diabetes prevalence in adults from two remote First Nations communities in northwestern Ontario, Canada. J Obes. 2011;2011:267509.

40. Adelson N. The embodiment of inequity: Health disparities in Aboriginal Canada. Can J Public Health. 2005;96(Suppl 2):S45-61.

41. Gracey M, King M. Indigenous health part 1: Determinants and disease patterns. Lancet. 2009;374(9683):65-75.

42. Pollex RL, Hanley AJ, Zinman B, Harris SB, Khan HM, Hegele RA. Synergism between mutant HNF1A and the metabolic syndrome in Oji-Cree type 2 diabetes. Diabet Med. 2005;22(11):1510-5.

43. Bellamy L, Casas JP, Hingorani AD, Williams D. Type 2 diabetes mellitus after gestational diabetes: A systematic review and meta-analysis. Lancet. 2009;373(9677):1773-9.

44. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. Canadian Diabetes Association 2013 clinical practice guidelines for the prevention and management of diabetes in Canada. Can J Diabetes. 2013;37(Suppl 1):S1-212.

45. International Association of Diabetes and Pregnancy Study Groups Consensus Panel, Metzger BE, Gabbe SG, Persson B, Buchanan TA, Catalano PA, et al. International association of diabetes and pregnancy study groups

recommendations on the diagnosis and classification of hyperglycemia in pregnancy. Diabetes Care. 2010;33(3):676-82.

46. Kjos SL, Buchanan TA. Gestational diabetes mellitus. N Engl J Med. 1999:341(23):1749-56.

47. HAPO Study Cooperative Research Group, Metzger BE, Lowe LP, Dyer AR, Trimble ER, Chaovarindr U, et al. Hyperglycemia and adverse pregnancy outcomes. N Engl J Med. 2008;58(19):1991-2002.

48. American Diabetes Association. Standards of medical care in diabetes – 2012. Diabetes Care. 2012;35(Suppl 1):S11-63.

49. Kapoor N, Sankaran S, Hyer S, Shehata H. Diabetes in pregnancy: A review of current evidence. Curr Opin Obstet Gynecol. 2007 Dec;19(6):586-90.

50. Langer O, Yogev Y, Most O, Xenakis EM. Gestational diabetes: The consequences of not treating. Am J Obstet Gynecol. 2005;192(4):989-97.

51. Aberg A, Westbom L, Kallen B. Congenital malformations among infants whose mothers had gestational diabetes or preexisting diabetes. Early Hum Dev. 2001;61(2):85-95.

52. Ben-Haroush A, Yogev Y, Hod M. Epidemiology of gestational diabetes mellitus. In: *Textbook of diabetes and pregnancy 2nd ed*. London, UK: Informa Healthcare; 2008: 118-31.

53. Xiong X, Saunders LD, Wang FL, Demianczuk NN. Gestational diabetes mellitus: Prevalence, risk factors, maternal and infant outcomes. Int J Gynaecol Obstet. 2001;75(3):221-8.

54. Cheung NW, Byth K. Population health significance of gestational diabetes. Diabetes Care. 2003;26(7):2005-9.

55. Retnakaran R, Shah BR. Mild glucose intolerance in pregnancy and risk of cardiovascular disease: A population-based cohort study. CMAJ. 2009;181(6-7):371-6.

56. Shah BR, Retnakaran R, Booth GL. Increased risk of cardiovascular disease in young women following gestational diabetes mellitus. Diabetes Care. 2008;31(8):1668-9.

57. MacNeill S, Dodds L, Hamilton DC, Armson BA, VandenHof M. Rates and risk factors for recurrence of gestational diabetes. Diabetes Care. 2001;24(4):659-62.

58. Bo S, Menato G, Botto C, Cotrino I, Bardelli C, Gambino R, et al. Mild gestational hyperglycemia and the metabolic syndrome in later life. Metab Syndr Relat Disord. 2006;4(2):113-21.

59. Davies GA, Maxwell C, McLeod L, Gagnon R, Basso M, Bos H, et al. Obesity in pregnancy. J Obstet Gynaecol Can. 2010;32(2):165-73.

60. Dabelea D. The predisposition to obesity and diabetes in offspring of diabetic mothers. Diabetes Care. 2007;30 Suppl 2:S169-74.

61. Silverman BL, Rizzo TA, Cho NH, Metzger BE. Long-term effects of the intrauterine environment. The northwestern university diabetes in pregnancy center. Diabetes Care. 1998;21(Suppl 2):B142-9.

62. Dahlquist G, Kallen B. School marks for Swedish children whose mothers had diabetes during pregnancy: A population-based study. Diabetologia. 2007;50(9):1826-31.

63. Ornoy A. Growth and neurodevelopmental outcome of children born to mothers with pregestational and gestational diabetes. Pediatr Endocrinol Rev. 2005;3(2):104-13.

64. Dionne G, Boivin M, Seguin JR, Perusse D, Tremblay RE. Gestational diabetes hinders language development in offspring. Pediatrics. 2008;122(5):e1073-9.

65. Jovanovic L. Achieving euglycaemia in women with gestational diabetes mellitus: Current options for screening, diagnosis and treatment. Drugs. 2004;64(13):1401-17.

66. Crowther CA, Hiller JE, Moss JR, McPhee AJ, Jeffries WS, Robinson JS, et al. Effect of treatment of gestational diabetes mellitus on pregnancy outcomes. N Engl J Med. 2005 Jun 16;352(24):2477-86.

67. Landon MB, Spong CY, Thom E, Carpenter MW, Ramin SM, Casey B, et al. A multicenter, randomized trial of treatment for mild gestational diabetes. N Engl J Med. 2009;361(14):1339-48.

68. Klinke J, Toth EL. Preconception care for women with type 1 diabetes. Can Fam Physician. 2003;49:769-73.

69. International Diabetes Federation. Global guideline on pregnancy and diabetes. Brussels, BE: International Diabetes Federation; 2009.

70. Massi-Benedetti M, Federici MO, Di Renzo GC. Management of gestational diabetes mellitus. In: *Textbook of diabetes and pregnancy 2nd ed*. London, UK: Informa Healthcare; 2008:188-95.

71. Gillman MW, Oakey H, Baghurst PA, Volkmer RE, Robinson JS, Crowther CA. Effect of treatment of gestational diabetes mellitus on obesity in the next generation. Diabetes Care. 2010;33(5):964-8.

72. Donovan LE. Gestational diabetes mellitus: Time to change our approach to screening, diagnosis and postpartum care? Can J Diabetes. 2010;23(1):7-10.

73. Reece EA, Leguizamon G, Wiznitzer A. Gestational diabetes: The need for a common ground. Lancet. 2009;373(9677):1789-97.

74. Daniells S, Grenyer BF, Davis WS, Coleman KJ, Burgess JA, Moses RG. Gestational diabetes mellitus: Is a diagnosis associated with an increase in maternal anxiety and stress in the short and intermediate term? Diabetes Care. 2003;26(2):385-9.

75. Rumbold AR, Crowther CA. Women's experiences of being screened for gestational diabetes mellitus. Aust N Z J Obstet Gynaecol. 2002;42(2):131-7.

76. Davenport MH, Mottola MF, McManus R, Gratton R. A walking intervention improves capillary glucose control in women with gestational diabetes mellitus: A pilot study. Appl Physiol Nutr Metab. 2008;33(3):511-7.

77. Snapp CA, Donaldson SK. Gestational diabetes mellitus: Physical exercise and health outcomes. Biol Res Nurs. 2008;10(2):145-55.

78. Riskin-Mashiah S, Damti A, Younes G, Auslender R. First trimester fasting hyperglycemia as a predictor for the development of gestational diabetes mellitus. Eur J Obstet Gynecol Reprod Biol. 2010;152(2):163-7.

79. Di Cianni G, Volpe L, Lencioni C, Miccoli R, Cuccuru I, Ghio A, et al. Prevalence and risk factors for gestational diabetes assessed by universal screening. Diabetes Res Clin Pract. 2003;62(2):131-7.

80. American College of Obstetricians and Gynecologists Committee on Practice Bulletins--Obstetrics. ACOG practice bulletin. clinical management guidelines for obstetrician-gynecologists. Number 30, September 2001 (replaces technical bulletin number 200, December 1994). Gestational diabetes. Obstet Gynecol. 2001;98(3):525-38.

81. Damm P. Future risk of diabetes in mother and child after gestational diabetes mellitus. Int J Gynaecol Obstet. 2009;104 Suppl 1:S25-6.

82. King H. Epidemiology of glucose intolerance and gestational diabetes in women of childbearing age. Diabetes Care. 1998;21 Suppl 2:B9-13.

83. Ferrara A, Kahn HS, Quesenberry CP, Riley C, Hedderson MM. An increase in the incidence of gestational diabetes mellitus: Northern California, 1991-2000. Obstet Gynecol. 2004;103(3):526-33.

84. Jovanovic L, Pettitt DJ. Gestational diabetes mellitus. JAMA. 2001;286(20):2516-8.

85. Public Health Agency of Canada. Diabetes in Canada. National statistics and opportunities for improved surveillance, prevention, and control. Ottawa, ON: Public Health Agency of Canada; 1999.

86. Reproductive Health Working Group. Alberta reproductive health: Pregnancies and births 2009. Edmonton, AB: Alberta Health and Wellness; 2009.

87. Feig DS, Palda VA. Type 2 diabetes in pregnancy: a growing concern. Lancet. 2002;359(9318):1690-2.

88. McEdluff A, Ross GP, Lagstrom JA, Champion B, Flack JR, Lau SM et al. Pregestational diabetes and pregnancy: an Australian experience. Diabetes Care. 2005;28(5):1260-1.

89. Balsells M, Garcia-Patterson A, Gich I, Corcoy R. Maternal and fetal outcome in women with type 2 versus type 1 diabetes mellitus: a systematic review and meta-analysis. J Clin Endocrinol Metab. 2009;94(11):4284-91.

90. Temple R, Murphy H. Type 2 diabetes in pregnancy: an increasing problem. Best Pract Res Clin Endocrinol Metab. 2010;24(4):591-603.

91. Aljohani N, Rempel BM, Ludwig S, Morris M, McQuillen K, Cheang M, et al. Gestational diabetes in Manitoba during a twenty-year period. Clin Invest Med. 2008;31(3):E131-7.

92. Wenman WM, Joffres MR, Tataryn IV, Edmonton Perinatal Infections Group. A prospective cohort study of pregnancy risk factors and birth outcomes in Aboriginal women. CMAJ. 2004;171(6):585-9.

93. Harris SB, Caulfield LE, Sugamori ME, Whalen EA, Henning B. The epidemiology of diabetes in pregnant Native Canadians. A risk profile. Diabetes Care. 1997;20(9):1422-5.

94. Willows ND, Sanou D, Bell RC. Assessment of Canadian Cree infants' birth size using the WHO Child Growth Standards. Am J Hum Biol. 2011;23(1):126-31.

95. Dabelea D, Knowler WC, Pettitt DJ. Effect of diabetes in pregnancy on offspring: follow-up research in the Pima Indians. J Matern Fetal Med. 2000;9(1):83-8.

96. Porter C, Skinner T, Ellis I. What is the impact of diabetes for Australian Aboriginal women when pregnant? Diabetes Res Clin Pract. 2011;93(1):e29-32.

97. Liu SL, Shah BR, Naqshbandi M, Tran V, Harris SB. Increased rates of adverse outcomes for gestational diabetes and pre-pregnancy diabetes in on-reserve First Nations women in Ontario, Canada. Diabet Med. 2012;29(8):e180-3.

98. Shah PR, Zao J, Al-Wassia H, Shah V, on behalf of Knowledge Synthesis Group on Determinants of Preterm/LBW Births. Pregnancy and neonatal outcomes of Aboriginal women: a systematic review and meta-analysis. Womens Health Issues. 2011;21(1):28-39.

99. Pettitt DJ, Jovanovic L. The vicious cycle of diabetes and pregnancy. Curr Diab Rep. 2077;7(4):295-7.

100. Feig DS, Zinman B, Wang X, Hux JE. Risk of development of diabetes mellitus after diagnosis of gestational diabetes. CMAJ. 2008;179(3):229-34.

101. Krishnaveni GV, Hill JC, Veena SR, Geetha S, Jayakumar MN, Karat CL, et al. Gestational diabetes and the incidence of diabetes in the 5 years following the index pregnancy in south Indian women. Diabetes Res Clin Pract. 2007;78(3):398-404.

102. Ho L, Gittelsohn J, Sharma S, Cao X, Treuth M, Rimal R, et al. Food-related behavior, physical activity, and dietary intake in First Nations - a population at high risk for diabetes. Ethn Health. 2008;13(4):335-49.

103. Mohamed N, Dooley J. Gestational diabetes and subsequent development of NIDDM in Aboriginal women of northwestern Ontario. Int J Circumpolar Health. 1998;57(Suppl 1):355-8.

104. Dabelea D, Hanson RL, Lindsay RS, Pettitt DJ, Imperatore G, Gabir MM, et al. Intrauterine exposure to diabetes conveys risks for type 2 diabetes and obesity: a study of discordant sibships. Diabetes. 2000;49(12):2208-11

105. Pettitt DJ, Aleck KA, Baird HR, Carraher MJ, Bennett PH, Knowler WC. Congenital susceptibility to NIDDM. Role of intrauterine environment. Diabetes. 1988;37(5):622-8.

106. Franks PW, Looker HC, Kobes S, Touger L, Tataranni PA, Hanson RL et al. Gestational glucose tolerance and risk of type 2 diabetes in young Pima Indian offspring. Diabetes. 2006;55(2):460-5.

107. Pettitt DJ, Lawrence JM, Beyer J, Hillier TA, Liese AD, Mayer-Davis B et al. Association between maternal diabetes in utero and age at offspring's diagnosis of type 2 diabetes. Diabetes Care. 2008;31(11):2126-30.

108. Barker DJP. The origins of the developmental origins theory. J Intern Med. 2007;261(5):412-7.

109. Barker DJ. The fetal and infant origins of adult disease. BMJ. 1990;301(6761):1111.

110. Portha B, Chavey A, Movassat J. Early-life origins of type 2 diabetes: fetal programming of the beta-cell mass. Exp Diabetes Res. 2011;Article ID 105076.

111. Dyck RF, Klomp H, Tan L. From "thrifty genotype" to "hefty fetal phenotype": the relationship between high birthweight and diabetes in Saskatchewan registered Indians. Can J Public Health. 2001;92(5):340-4.

112. Osgood ND, Dyck RF, Grassmann WK. The inter- and intragenerational impact of gestational diabetes on the epidemic of type 2 diabetes. Am J Public Health. 2011;101(1):173-9.

113. Mendelson M, Cloutier J, Spence L, Sellers E, Taback S, Dean H. Obesity and type 2 diabetes mellitus in a birth cohort of First Nation children born to mothers with pediatric-onset type 2 diabetes. Pediatric Diabetes. 2011;12(3):219-28.

114. Alwan N, Tuffnell DJ, West J. Treatments for gestational diabetes. Cochrane Database Syst Rev. 2009;3:CD003395.

115. Ceysens G, Rouiller D, Boulvain M. Exercise for diabetic pregnant women. Cochrane Database Syst Rev. 2006;3:CD004225.

116. Callaway LK, Colditz PB, Byrne NM, Lingwood BE, Rowlands IJ, Foxcroft K, et al. Prevention of gestational diabetes: Feasibility issues for an exercise intervention in obese pregnant women. Diabetes Care. 2010;33(7):1457-9.

117. Dye TD, Knox KL, Artal R, Aubry RH, Wojtowycz MA. Physical activity, obesity, and diabetes in pregnancy. Am J Epidemiol. 1997;146(11):961-5.

118. Tieu J, Crowther CA, Middleton P. Dietary advice in pregnancy for preventing gestational diabetes mellitus. Cochrane Database Syst Rev. 2008;2:CD006674.

119. Hui AL, Ludwig SM, Gardiner P, Sevenhuysen G, Murray R, Morris M, et al. Community-based exercise and dietary intervention during pregnancy: A pilot study. Can J Diabetes. 2006;30(2):169-75.

120. Gray-Donald K, Robinson E, Collier A, David K, Renaud L, Rodrigues S. Intervening to reduce weight gain in pregnancy and gestational diabetes mellitus in Cree communities: An evaluation. CMAJ. 2000;163(10):1247-51.

121. Klomp H, Dyck R, Sheppard S. Description and evaluation of a prenatal exercise program for urban Aboriginal women. Can J Diabetes. 2003;27(3):231-238.

122. Willows ND. Determinants of healthy eating in Aboriginal peoples in Canada: The current state of knowledge and research gaps. Can J Public Health. 2005;96(Suppl 3):S32-6.

123. Benoit C, Carroll D, Chaudhry M. In search of a healing place: Aboriginal women in Vancouver's downtown eastside. Soc Sci Med. 2003;56(4):821-33.

124. MacKinnon M. A First Nations voice in the present creates healing in the future. Can J Public Health. 2005;96(Suppl 1):S13-6.

125. King KM, Sanguins J, McGregor L, LeBlanc P. First Nations people's challenge in managing coronary artery disease risk. Qual Health Res. 2007;17(8):1074-87.

126. Zubek EM. Traditional Native healing. Alternative or adjunct to modern medicine? Can Fam Physician. 1994;40:1923-31.

127. Rothe JP, Makokis P, Steinhauer L, Aguiar W, Makokis L, Brertton G. The role played by a former federal government residential school in a First Nation

community's alcohol abuse and impaired driving: Results of a talking circle. Int J Circumpolar Health. 2006;65(4):347-56.

128. Smylie J, Kaplan-Myrth N, Tait C, Martin CM, Chartrand L, Hogg W, et al. Health sciences research and Aboriginal communities: pathway or pitfall? J Obstet Gynaecol Can. 2004;26(3):211-6.

129. Garner R, Carrière G, Sanmartin C, the Longitudinal Health and Administrative Data Research Team. The health of First Nations living off-reserve, Inuit, and Métis adults in Canada: The impact of socio-economic status on inequalities in health. Ottawa, ON: Statistics Canada; 2010.

130. Nicolaisen I. Cultural perceptions, gestational diabetes, and development. Int J Gynaecol Obstet. 2009;104(Suppl 1):S8-10.

131. Evans MK, O'Brien B. Gestational diabetes: The meaning of an at-risk pregnancy. Qual Health Res. 2005;15(1):66-81.

132. Hjelm K, Bard K, Nyberg P, Apelqvist J. Management of gestational diabetes from the patient's perspective--a comparison of Swedish and middle-eastern born women. J Clin Nurs. 2007;16(1):168-78.

133. Hjelm K, Bard K, Nyberg P, Apelqvist J. Swedish and middle-eastern-born women's beliefs about gestational diabetes. Midwifery. 2005;21(1):44-60.

134. Persson M, Winkvist A, Mogren I. 'From stun to gradual balance' - women's experiences of living with gestational diabetes mellitus. Scand J Caring Sci. 2009;24(3):454-62.

135. Marquez DX, Bustamante EE, Bock BC, Markenson G, Tovar A, Chasan-Taber L. Perspectives of Latina and non-Latina white women on barriers and facilitators to exercise in pregnancy. Women Health. 2009;49(6):505-21.

CHAPTER 2

Research Approach Overview

2.1 Introduction and Hypotheses

This chapter provides a general overview of my doctoral research that was part of a larger plan aimed at examining diabetes in pregnancy among Aboriginal women, with the ultimate future goal of developing interventions that can effectively improve care for diabetes in pregnancy. It is assumed that improved processes of care will lead to better outcomes (1). Long-term subsequent goals include decreasing diabetes in pregnancy and its associated risks (and thus future type 2 diabetes). A multiphase mixed methods research approach is being utilized (2), whereby this thesis encompassed the initial two phases that were concurrent and incremental. Phase 1 used provincial administrative data whereas phase 2 used qualitative data generated with First Nations women residing in Edmonton (Alberta) and surrounding communities. In a final step, the findings from both phases were integrated and considered together.

Regarding phase 1, it was hypothesized that diabetes in pregnancy rates in First Nations women would be significantly higher than the general population, and First Nations women with diabetes in pregnancy would have an increased risk of adverse pregnancy outcomes compared to those without diabetes in pregnancy. These results would be similar to Dyck et al (3) and Aljohani et al (4, 5). In phase 2, it was anticipated that First Nations women with diabetes in pregnancy would have experienced a lack of culturally sensitive care and holistic First Nations traditional healing practices during their pregnancy. It was also anticipated that interconnected social and health problems would present barriers to the

appropriate diabetes in pregnancy management and resultant pregnancies would be tremendously difficult (6).

2.2 Mixed Methods Research Design

Mixed methods research is a growing field, and using a mixed methods approach has become increasingly more common in health research. Although a consistent definition has not been established, mixed methods research can be loosely viewed as the use of designs that incorporate both quantitative and qualitative methods (7). It has been argued that the essence of mixed methods research is in the integration of quantitative and qualitative findings to yield rich understandings unattainable through use of the two components separately (7). In this thesis, the definition described by Creswell and Plano Clark (2) was followed: "a design for collecting, analyzing, and mixing both quantitative and qualitative research (or data) in a single study or a series of studies to understand a research problem".

Numerous mixed methods study designs exist and the choice of design depends on the study purpose (2). A multiphase design proceeds outside the basic mixed method designs (convergent, explanatory, exploratory and embedded) to address a series of incremental and connected research questions over a period of time progressing to a single overall research objective (2). Such a design supplies an overarching methodological agenda to a multiyear project that necessitates multiple phases and techniques (both qualitative and quantitative) to develop a general program of research. According to Creswell and Plano Clark (2), the

phases can occur concurrently or sequentially. A multiphase design was fitting for the current research project as the overall research goal could not be achieved within a single study, and since the impact of diabetes in pregnancy in First Nations populations is an emerging area of research, new questions are expected to arise during the different phases of the research project. Figure 2.1 depicts the overall multiphase mixed methods approach that was utilized. Below is a brief description of both the quantitative and qualitative phases, as well as the data integration approach. Detailed methodology of the specific phases is provided in the corresponding chapters.

2.2.1 Quantitative Phase

In countries with universal healthcare, administrative data have become a common and invaluable source for the population-based surveillance of many chronic diseases. In Alberta specifically, administrative perinatal information is comprehensively collected by the Alberta Perinatal Health Program (APHP) from delivery records and from mortality case reviews (Vital Statistics Death Registration Files). Having the opportunity to access APHP databases was key to the quantitative phase aimed at generating an epidemiological profile of First Nations diabetes in pregnancy in Alberta.

Quantitative research is the empirical investigation and analysis of numerical data with the aim of determining the relationship between an independent variable and dependant variable(s), and is often categorized into experimental and observational designs (8). In observational studies, the investigator has no control over the assignment of subjects to groups and thus

Figure 2.1 Organization of the multiphase mixed methods design

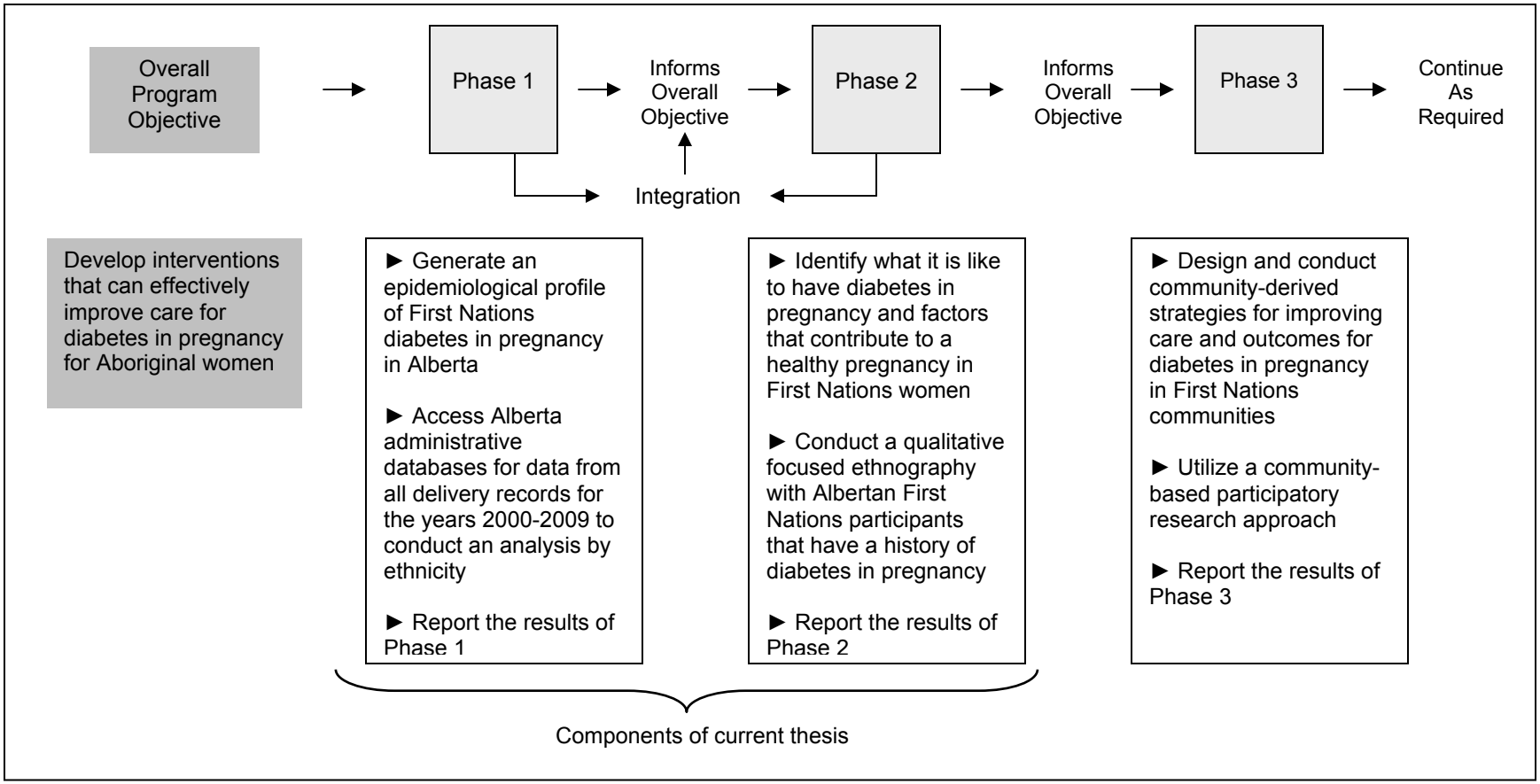


Figure adapted from Creswell and Plano Clark (2)

observes records and behaviors, rather than attempting to change them (8). Epidemiology is a branch of observational research that studies the distribution and determinants of health and disease conditions. Given the nature of the available APHP data, a longitudinal retrospective observational study design was utilized to understand the extent of the problem of diabetes in pregnancy among First Nations women. Briefly, de-identified data from all delivery records of adult women were obtained from the APHP for the years 2000-2009. First Nations women were identified by the Ministry of Alberta Health and Wellness (AHW). Pregestational, past obstetrical, and delivery outcomes and problems were described. Annual age-adjusted rates of diabetes in pregnancy by ethnicity were calculated and compared. Longitudinal changes in prevalence over time were also computed and compared. Finally, the predictors of diabetes in pregnancy were explored through logistic regression analyses.

2.2.2 Qualitative Phase

It was expected that ethnic differences in predictors, rates, and outcomes of diabetes in pregnancy would be observed in the quantitative study. Although such data is tremendously valuable, to stop there would mean failing to explore the underlying reasons of these observations. The quantitative data reveals a great deal about 'how many' and 'how much', but does little in the comprehension of equally important 'how' and 'why' questions. Thus, a qualitative approach was utilized to explore 'the stories behind the numbers' and to bring to light what might contribute to achieving a healthy pregnancy among First Nations women with diabetes in pregnancy.

Qualitative research is an inductive approach to understand and interpret the meanings attributed by people that experience a certain phenomena (9). Many qualitative methods exist, including phenomenology, grounded theory, and ethnography, to name a few. As with any type of research, the methods used depend upon the research question(s) being asked and the population being studied. Ethnography imparts an in-depth account of phenomena from the point of view of a cultural group (10). Focused ethnography in particular, is used in unambiguous contexts where there is a distinctive problem (e.g. high rates and poor outcomes of diabetes in pregnancy among First Nations women) with specific research questions (e.g. what is it like to have diabetes in pregnancy and what factors contribute to achieving a healthy pregnancy in First Nations women?; 10). The findings of focused ethnographies are often used to contribute to decision making (e.g. devising an intervention to improve care for diabetes in pregnancy for First Nations women; 10). Accordingly, focused ethnography was chosen as the best method in the current thesis.

Briefly, First Nations adult women that had at least one instance of diabetes in pregnancy within the previous five years were recruited from Edmonton and/or from surrounding communities via convenience sampling. Unstructured interviews with participants were carried out until data saturation was reached. Interviews were recorded and transcribed (verbatim) and all of the data was subject to qualitative content analysis.

2.2.3 Data Integration

Despite the increase in mixed methods designs, the degree to which data 'mixing' occurs has been shown to be limited (7). The impetus for integrating the quantitative and qualitative data was to answer the project research questions more comprehensively as the qualitative data was expected to help explain the quantitative data and vice versa. To help uncover the practical implications of this thesis, the qualitative and quantitative findings were integrated through a triangulation protocol adapted from Creswell and Plano Clark (2).

2.2.4 Ethics, Data Storage and Confidentiality

Each phase received ethical approval from the Human Research Ethics Board of the University of Alberta. Details on specific ethical issues are discussed in Chapters 3 and 4. However, it should be noted here that based on the ethical guidelines of the Tri-Council Policy Statement - 2 Research Involving the First Nations, Inuit and Métis Peoples of Canada (Article 9.2 and Article 9.22), First Nations community engagement was not necessary and/or impossible given the nature of the two study designs (11).

Confidentiality was ensured as access to all data was restricted to only the research team. All data was kept on either a password protected terminal server or within encrypted files. The quantitative data was received from AHW in a de-identified format. Qualitative participants and their respective communities remained unidentifiable throughout the study, and codes were used as identifiers.

2.3 Summary

This thesis encompasses the initial two phases of a planned large multiphase project, and it was expected that the findings would inform future phases. The first two phases were designed to understand the extent of the problem of diabetes in pregnancy in First Nations women and to understand how a healthier pregnancy could be achieved for these women. The next planned phase is thus out of the scope of this thesis, but will essentially be a knowledge translation piece where a community-based participatory research approach will be followed to design and implement strategies for improving the care for pregnant First Nations women with diabetes.

2.4 References

1. Alwan N, Tuffnell DJ, West J. Treatments for gestational diabetes. Cochrane Database Syst Rev. 2009;3:CD003395.

2. Creswell J, Plano Clark VL. *Designing and Conducting Mixed Methods Research 2nd Edition*. Thousand Oaks, CA: SAGE Publications; 2011.

3. Dyck R, Klomp H, Tan LK, Turnell RW, Boctor MA. A comparison of rates, risk factors, and outcomes of gestational diabetes between Aboriginal and non-Aboriginal women in the Saskatoon health district. Diabetes Care. 2002;25(3):487-93.

4. Aljohani N, Rempel BM, Ludwig S, Morris M, McQuillen K, Cheang M, et al. Gestational diabetes in Manitoba during a twenty-year period. Clin Invest Med. 2008;31(3):E131-7.

5. Aljohani N, Rempel BM, Ludwig S, Morris M, Cheang M, Murray R, et al. Impact of diabetes on maternal-fetal outcomes in Manitoba: Relationship with ethnic and environmental factors. Clin Invest Med. 2008;31(6):E338-45.

6. King M, Smith A, Gracey M. Indigenous health part 2: The underlying causes of the health gap. Lancet. 2009;374(9683):76-85.

7. Johnson BR, Onwuegbuzie A, Turner LA. Towards a definition of mixed methods research. J Mixed Methods Res. 2007;1(2):112-33.

8. McBurney DH, White TL. *Research Methods 7th Edition*. Belmont, CA: Thompson Education; 2007.

9. Mayan MJ. *Essentials of Qualitative Inquir*y. Walnut Creek, CA: Left Coast Press, Inc; 2009.

10. Savage J. Ethnography and health care. British Medical Journal (Clinical Research Ed.). 2000;321(7273):1400-1402.

11. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada*. 2010.

CHAPTER 3

An Epidemiological Profile of Diabetes in Pregnancy among First Nations and non-First Nations Women in Alberta

3.1 Introduction

Diabetes in pregnancy, including both gestational diabetes mellitus (GDM) and pregestational diabetes, is a major risk factor for future obesity and type 2 diabetes in mothers and their offspring (1-3), and is considered a key contributor to the ongoing increases in diabetes worldwide, particularly in Indigenous populations (4). In Canada, prevalence and incidence rates of diabetes have increased rapidly in First Nations groups over the past half century, such that they are currently 2-5 times greater than non-First Nations populations (5-7). As opposed to the general population, First Nations women generally suffer higher diabetes rates than their male counterparts, presumably due in-part to a rise in diabetes in pregnancy (4, 6, 7).

GDM and some related adverse pregnancy outcomes appear to be more common among First Nations women than non-First Nations women (8-12). For instance, data from a large retrospective cohort in Ontario recently found diabetes in pregnancy (both GDM and pregestational diabetes) prevalence was 10.3% among First Nations women compared to 6.0% in non-First Nations women (9). Also, rates of preterm delivery, high birth weight (HBW), jaundice, neonatal hypoglycemia and shoulder dystocia were significantly higher among the First Nations women with diabetes in pregnancy (9). Similar findings have been reported in Saskatchewan, Manitoba, and Quebec (10-12).

It is believed that prevention of diabetes in pregnancy and enhanced care for women with diabetes in pregnancy will help reduce the burden of type 2 diabetes in First Nations populations (2, 13-16). However, diabetes in pregnancy

among First Nations women is a growing area of research and many gaps in knowledge currently exist. What is known of epidemiology is based primarily on cross-sectional studies focusing on GDM, as longitudinal data and pregestational diabetes data are limited. As well, other important maternal factors and pregnancy outcomes have yet to be explored in this population in relation to both GDM and pregestational diabetes in pregnancy. For these reasons, the current study sought to use provincial administrative data on pregnancies to generate an epidemiological profile of First Nations diabetes in pregnancy in Alberta. The following overall research questions were considered: 1) what are the prevalence rates of diabetes in pregnancy and related outcomes among First Nations and non-First Nations women in Alberta?; 2) how do diabetes in pregnancy rates differ by ethnicity and how have they changed over time?; and 3) what are the predictors of diabetes in pregnancy among Albertan women?

3.2 Methods

Prior to data acquisition from the Alberta Perinatal Health Program (APHP), ethical approval was obtained from the Human Research Ethics Board of the University of Alberta. The APHP collects perinatal data from the provincial delivery record (see appendix 1) for all hospital births and registered midwife attended home births in Alberta (data is available from 1998). Pertinent de-identified data from all delivery records was requested for the years 2000-2009. Descriptions of the variables included in the analyses are presented in Table 3.1. Data were complete or near complete (available for 97%- 100% of pregnancies)

Table 3.1 Description of included variables amongst 427,058 pregnancies.	
Pregestational	
Age (n = 426,335)	Maternal age in years
Weight ≤ 45 kg (n = 426,913)	Maternal pregestational weight ≤ 45 kg
Weight ≥ 91 kg (n = 426,913)	Maternal pregestational weight ≥ 91 kg
Hypertension (n = 427,058)	Pregestational blood pressure ≥ 140/90 mmHg and/or taking antihypertensive drugs
Chronic renal disease (n = 427,058)	Pregestational diagnosis of chronic renal disease
Diabetes retinopathy (n = 427,058)	Pregestational diagnosis of diabetic retinopathy
Past obstetrical history	
Parity (n = 424,598)	Number of previous pregnancies ≥ 20 weeks gestation excluding current
Preterm (n = 262,459)	Infants born between 20 and < 37 weeks excluding current (southern Alberta did not collect until 2007)
Neonatal death (n = 427,058)	History of a death of an infant that was born alive and aged < 29 days
Stillbirth (n = 427,058)	History of birth (after ≥ 20 weeks or attaining a weight of ≥ 500g) of a fetus that has died in utero
Abortion (n = 427,058)	History of abortion between 12 to 20 weeks and < 500 g weight (therapeutic and spontaneous)
Cesarean section (n = 427,058)	History of cesarean section
Small for gestational age (SGA; n = 427,058)	History of infant birth weight < 5^{th} percentile for gestational age
Large for gestational age (LGA; n = 427,058)	History of infant birth weight > 95^{th} percentile for gestational age
Major fetal anomaly (n = 427,058)	History of fetus with any anomaly that was lethal, required corrective surgery or had a major effect on growth, development or quality of life
Problems in current pregnancy	
Multiple pregnancy (n = 427,058)	Multiple gestation (twins, triplets, etc.)
Pregnancy induced hypertension (PIH; n = 427,058)	Diagnosis of gestational hypertension with current pregnancy
Proteinuria (n = 427,058)	Diagnosis of proteinuria with current pregnancy
Insufficient weight gain (n = 427,058)	Weight gain between 26 and 36 weeks of < 0.5 kg/week or weight loss with current pregnancy
Anemia (n = 427,058)	Anemia (hemoglobin < 100 g/L) with current pregnancy
Pregnancy ≥ 41 weeks (426,462)	Gestational age at delivery ≥ 41 weeks
Smoker (n = 427,058)	Smoker anytime during pregnancy
Alcohol ≥ 1 drink per day (n = 414,404)	Alcohol ≥ 1 drink per day throughout pregnancy
Alcohol ≥ 3 drinks ever (n = 414,404)	Alcohol ≥ 3 drinks on any one occasion during current pregnancy
Drug dependant (n = 414,549)	Inappropriate/excessive use of a substance that may adversely affect the pregnancy or newborn

Table 3.1 (continued)	
Antepartum risk score (n = 426,951)	Sum of the weighted values for antepartum risk assessment factors from the delivery record (see Appendix 1)
High antepartum risk (n = 426,951)	Sum of the weighted values for antepartum risk assessment factors from the delivery record is ≥ 7
Labour and newborn outcomes	
Induction of labour (n = 427,018)	Woman had induced labour in current pregnancy
APGAR 1 min (n = 426,357)	APGAR score assessed at 1 minute
APGAR 5 min (n = 426,325)	APGAR score assessed at 5 minutes
Birth weight (n = 426,235)	First weight of newborn after birth, in grams
Low birth weight (LBW; n = 426,235)	First weight of newborn after birth ≤ 2500 g (see reference 16)
High birth weight (HBW; n = 426,235)	First weight of newborn after birth ≥ 4000 g (see reference 16)
Gestational age (n = 426,462)	Gestational age at delivery in weeks
Breastfeeding (n = 141,985)	Infant breastfed either after delivery or upon on discharge (data not available province-wide)
Preterm (n = 426,462)	Infant born to this woman between 20 and < 37 completed weeks gestation in current birth
Stillbirth (n = 427,058)	Birth (after ≥ 20 weeks or attaining a weight of ≥ 500 g) of a fetus that has died in utero
Neonatal intensive care unit (NICU) admission (n = 417,751)	Baby admitted to NICU as the clinical care that is required is beyond that of a healthy newborn
Major congenital anomaly (n = 414,549)	Presence of major fetal anomaly at birth
Cesarean section (n = 427,058)	Cesarean section delivery method
Vaginal breech (n = 427,058)	Vaginal breech delivery

for the majority of variables. History of a preterm infant was available for only 62% of pregnancies as southern Alberta did not collect this data until 2007. Data on breastfeeding was not available province-wide, and just 33% of pregnancies had breastfeeding data. Therefore, data on history of preterm infants and breastfeeding were used only for descriptive purposes.

In addition to the APHP variables listed in Table 3.1, the Ministry of Alberta Health & Wellness (AHW), Surveillance Division, via access to the Alberta Health Care Insurance Plan Central Stakeholder Registry file, was utilized to identify those with registered Indian (First Nations) status. Data obtained from the APHP was sent to AHW for data matching via the Personal Health Number for First Nations identification. First Nations individuals were defined as any Alberta resident registered under the Indian Act of Canada and entitled to Treaty status with the Canadian Government. A woman delivering in Alberta with a First Nations identifier (First Nations or Inuit) was classified as "First Nations". Both on- and off-reserve Status First Nations individuals were included. Non-registered Aboriginal persons, such as First Nations individuals without Treaty status or Métis individuals, were included in the general population comparison group. De-identified complete data was returned by AHW in STATA format.

3.2.1 Statistical Analyses

All analyses were conducted using STATA statistical software (version 11; College Station, Texas, United States) and Joinpoint (version 3.5.1; Rockville, Maryland, United States). Prevalence and means of pregestational maternal risk factors, past obstetrical history variables, problems with current pregnancy,

maternal outcomes and newborn outcomes were calculated. Comparisons were made by ethnicity among both those without diabetes and those with diabetes. Also, differences between First Nations women with and without diabetes were explored. Finally, among First Nations women with diabetes alone, comparisons by diabetes type were made. Comparisons were made using Chi-square analysis (for categorical variables) and t-tests (for continuous variables).

Annual age-adjusted prevalence rates of GDM and pregestational diabetes for the entire province by ethnicity were calculated by the direct method. The maternal age distribution of the total number of pregnancies in 2005 from the Canadian Vital Statistics was used as the standard population (17). Crude prevalence rates were also calculated to make comparisons with previous studies. For longitudinal analyses, the Average Annual Percent Change (AAPC) in GDM and pregestational diabetes prevalence over time were computed and compared between ethnicities. The AAPC provides a summary measure of the trend over a pre-specified fixed interval (2000-2009). Tests of parallelism were then performed to determine if trends over time differed by ethnicity.

Statistical modelling (purposeful) using logistic regression was used to evaluate the relationships between GDM and potential explanatory variables (pregestational maternal risk factors, past obstetrical history variables, problems with current pregnancy). Logistic regression was repeated with pregestational diabetes as the dependant variable. Briefly, independent variables that were significant ($p < 0.20$) in univariate linear regression were fitted in a multi-variable model. Those variables not significant at $p < 0.05$ were removed and their

potential confounding effect was assessed. The linear assumptions of continuous variables and potential interaction effects were assessed. Finally, the Hosmer-Lemshow test was used to determine model goodness-of-fit. Total antenatal risk score was not utilized as it is inclusive of many of the other variables and thus introduced co-linearity problems. To further reduce co-linearity, the variables alcohol ≥ 1 drink per day and alcohol ≥ 3 drinks ever were combined into a single variable.

3.3 Results

3.3.1 Descriptive Analyses

According to the APHP, between 2000 and 2009 there were 433,445 pregnancies in Alberta. Diabetes data was missing for 6,387 records, of which 449 (7.0%) were from First Nations women, and were not included in analyses. Thus 427,058 pregnancy records were explored, of which 28,306 (6.6%) were from First Nations women. If a woman had more than one pregnancy in the period of observation all pregnancies were used in the analyses. The number of pregnancies where diabetes data was available by year, age group, and ethnicity are shown in Table 3.2. The majority (52.3%) of First Nations pregnancies were among women < 25 years of age whereas only 22.5% of non-First Nations women fell into this category.

Comparisons in pregestational maternal risk factors, past obstetrical history variables, problems with current pregnancy, and outcomes are shown in Table 3.3. In general, First Nations women tended to have more risk factors and

Table 3.2 Demographic breakdown of pregnancies (n = 427,058) by age group and ethnicity in Alberta, 2000-2009*.

	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	% of total pregnancies
< 15											
First Nations	7	5	5	9	8	8	5	10	6	12	0.3%
Non-First Nations	9	14	13	6	12	6	18	18	14	8	0.0%
15-19											
First Nations	516	526	510	497	498	570	564	585	642	677	19.8%
Non-First Nations	1,863	1,733	1,698	1,600	1,567	1,544	1,704	1,849	1,797	1,685	4.3%
20-24											
First Nations	800	751	847	900	912	924	965	985	1,035	1,060	32.5%
Non-First Nations	6,473	6,663	6,889	7,087	6,913	7,010	7,582	8,027	7,993	7,781	18.2%
25-29											
First Nations	531	596	660	654	635	651	740	820	882	878	24.9%
Non-First Nations	10,500	10,681	11,089	11,638	11,977	12,445	13,203	14,521	15,261	15,765	31.9%
30-34											
First Nations	346	358	374	390	414	390	439	469	507	516	14.9%
Non-First Nations	9,380	10,031	10,519	11,029	11,235	11,606	12,451	13,349	14,197	14,716	29.8%
35-40											
First Nations	157	151	142	168	168	163	182	203	214	225	6.3%
Non-First Nations	4,401	4,514	4,620	4,801	4,818	5,096	5,525	6,091	6,440	6,552	13.3%
≥40											
First Nations	25	43	26	39	31	36	34	35	44	52	1.3%
Non-First Nations	758	794	816	979	972	1,028	1,051	1,181	1,203	1,299	2.5%
Total											
First Nations	2,399	2,457	2,566	2,662	2,672	2,743	2,935	3,121	3,331	3,420	28,306
Non-First Nations	33,527	34,581	35,688	37,192	37,539	38,775	41,588	45,109	46,942	47,811	398,752

* Includes pregnancies with diabetes data only

Table 3.3 Maternal characteristics, antenatal risk factors and pregnancy outcomes of pregnancies (n = 427,058) by ethnicity and diabetes in pregnancy status in Alberta, 2000-2009. Values are prevalence per 100 (95% CI) or mean (SD) as appropriate.

	Pregnant women without diabetes (n = 407,855)			Pregnant women with diabetes (n = 19,173)		
	First Nations (n = 26,793)	Non-First Nations (n = 381,092)	p-value	First Nations (n = 1,513)	Non-First Nations (n = 17,660)	p-value
Pregestational						
Age (years)	24.7 (5.81)*	28.7 (5.45)	**<0.001**	28.9 (6.22)*	31.6 (5.27)	**<0.001**
Age ≤ 17	8.1% (7.78-8.43)*	1.2% (1.18-1.25)	**<0.001**	2.7% (3.31-5.56)*	0.2% (0.17-0.32)	**<0.001**
Age ≥ 35	6.9% (6.57-7.18)*	15.2% (15.04-15.27)	**<0.001**	20.0% (17.99-22.08)*	30.0% (29.35-30.71)	**<0.001**
Rural	51.8% (51.21-52.41)	15.9 (15.75-15.98)	**<0.001**	52.5% (49.93-55.02)	11.4% (10.92-11.86)	**<0.001**
Weight ≤ 45 kg	0.4% (0.38-0.54)	0.6% (0.53-0.58)	**0.034**	0.7% (0.32-1.22)	0.7% (0.57-0.82)	0.914
Weight ≥ 91 kg	10.8% (10.47-11.22)*	8.0% (7.94-8.12)	**<0.001**	31.7% (29.34-34.09)*	18.4% (17.86-19.01)	**<0.001**
Hypertension	0.9% (0.79-1.00)*	0.9% (0.91-0.97)	0.367	4.2% (3.27-5.37)*	3.3% (2.99-3.52)	**0.041**
Chronic renal disease	0.1% (0.05-0.12)*	0.1% (0.08-0.10)	0.419	0.3% (0.11-0.77)*	0.1% (0.07-0.18)	**0.025**
Diabetic retinopathy	--	--	--	0.4% (0.15-0.86)	0.4% (0.26-0.44)	0.746
Past obstetrical history						
Parity	1.7 (1.86)*	0.9 (1.12)	**<0.001**	2.2 (2.10)*	1.1 (1.35)	**<0.001**
Preterm	8.3% (7.93-8.65)*	4.8% (4.74-4.92)	**<0.001**	12.8% (11.03-14.81)*	7.9% (7.34-8.41)	**<0.001**
Neonatal death	1.0% (0.88-1.12)*	0.5% (0.50-0.55)	**<0.001**	1.7% (1.07-2.43)*	0.9% (0.78-1.06)	**0.005**
Stillbirth	1.9% (1.70-2.03)*	0.9% (0.86-0.92)	**<0.001**	5.0% (3.92-6.17)*	2.2% (2.00-2.44)	**<0.001**
Abortion	7.3% (6.94-7.57)*	4.9% (4.86-5.00)	**<0.001**	9.1% (7.66-10.61)*	6.0% (5.69-6.40)	**<0.001**
Cesarean section	11.6% (11.18-11.95)*	12.2% (12.12-12.33)	**0.001**	20.2% (18.23-22.34)*	18.9% (18.31-19.47)	0.202
SGA	0.7% (0.62-0.83)*	0.7 % (0.64-0.70)	0.318	0.3% (0.07-0.68)*	0.7% (0.61-0.86)	**0.038**
LGA	1.6% (1.44-1.74)*	1.0% (1.00-1.07)	**<0.001**	6.9% (5.71-8.34)*	3.0% (2.71-3.21)	**<0.001**
Major fetal anomaly	0.8% (0.71-0.93)	0.6% (0.58-0.64)	**0.002**	1.1% (0.66-1.79)	0.8% (0.70-0.98)	0.238
Problems in current pregnancy						
Multiple pregnancy	2.9% (2.67-3.07)	3.4% (3.30-3.42)	**<0.001**	3.5% (2.63-4.56)	3.9% (3.58-4.27)	0.370
PIH	4.4% (4.15-4.65)*	5.7% (5.59-5.73)	**<0.001**	8.1% (6.66-9.65)*	12.2% (11.70-12.67)	0.193
Proteinuria	2.4% (2.24-2.61)*	1.9% (1.86-1.95)	**<0.001**	5.6% (4.51-6.90)*	3.9% (3.58-4.15)	**0.001**
Insufficient weight gain	1.2% (1.03-1.29)	1.5% (1.44-1.52)	**<0.001**	1.5% (0.91-2.19)	2.2% (2.02-2.46)	**0.046**
Anemia	2.3% (2.12-2.49)*	0.6% (0.53-0.60)	**<0.001**	1.3% (0.81-2.03)*	0.5% (0.43-0.65)	**<0.001**

Table 3.3 (continued)

	Pregnant women without diabetes (n = 407,855)			Pregnant women with diabetes (n = 19,173)		
	First Nations (n = 26,793)	Non-First Nations (n = 381,092)	p-value	First Nations (n = 1,513)	Non-First Nations (n = 17,660)	p-value
Pregnancy ≥ 41 weeks	13.8% (13.42-14.25)*	14.4% (14.33-14.56)	**0.006**	5.1% (4.05-6.33)*	4.3% (4.05-4.66)	0.172
Smoker	54.7% (54.07-55.26)*	17.0% (16.92-17.16)	**<0.001**	49.4% (46.82-51.92)*	14.3% (13.78-14.82)	**<0.001**
Alcohol ≥ 1 drink per day	0.9% (0.81-1.05)	0.1% (0.10-0.12)	**<0.001**	0.6% (0.28-1.15)	0.1% (0.02-0.09)	**<0.001**
Alcohol ≥ 3 drinks ever	9.5% (9.15-9.86)*	1.6% (1.54-1.62)	**<0.001**	7.2% (5.93-8.63)*	0.9% (0.75-1.04)	**<0.001**
Drug dependant	6.6% (6.25-6.85)*	0.9% (0.88-0.94)	**<0.001**	3.5% (2.62-4.56)*	0.4% (0.30-0.49)	**<0.001**
Antepartum risk score	2.9 (2.74)*	2.1 (2.27)	**<0.001**	5.6 (3.56)*	4.4 (2.95)	**<0.001**
High antepartum risk (≥ 7)	10.4% (10.07-10.81)*	5.1% (5.05-5.19)	**<0.001**	30.7% (28.42-33.13)*	19.8% (19.22-20.40)	**<0.001**
Labour and newborn outcomes						
Induction of labour	23.8% (23.31-24.33)*	27.3% (27.14-27.42)	**<0.001**	41.7% (39.21-44.24)*	40.9% (40.20-41.65)	0.554
APGAR 1 min	7.8 (1.99)*	7.9 (1.73)	**0.011**	7.5 (2.07)*	7.8 (1.92)	**<0.001**
APGAR 5 min	8.9 (1.36)*	8.8 (1.12)	**<0.001**	8.6 (1.58)*	8.8 (1.08)	**0.002**
Birth weight (grams)	3411.5 (705.95)*	3338.5 (620.77)	**<0.001**	3577.5 (805.35)*	3326.8 (653.06)	**<0.001**
LBW	8.0% (7.63-8.28)	7.1% (6.99-7.16)	**<0.001**	7.2% (5.96-8.64)	8.6% (8.20-9.03)	0.063
HBW	16.7% (16.25-17.15)*	11.1% (10.89-11.09)	**<0.001**	29.3% (26.97-31.62)*	12.9% (12.38-13.37)	**<0.001**
Gestational age (months)	38.5 (2.71)*	38.7 (2.37)	**<0.001**	37.8 (2.65)*	38.0 (2.14)	**0.007**
Breastfeeding	71.2% (70.45-72.83)	88.3% (88.20-88.55)	**<0.001**	74.7% (69.26-79.55)	86.3% (85.42-87.07)	**<0.001**
Preterm	9.2% (8.88-9.58)*	8.8% (8.73-8.91)	**0.026**	17.3% (15.41-19.29)*	14.7% (14.23-15.28)	**0.008**
Stillbirth	1.2% (1.06-1.33)*	0.7% (0.63-0.68)	**<0.001**	2.1% (1.45-2.97)*	0.6% (0.52-0.76)	**<0.001**
NICU admission	8.6% (8.28-8.96)*	11.2% (11.06-11.27)	**<0.001**	16.7% (14.81-15.66)*	19.4% (18.83-20.02)	**<0.001**
Congenital anomaly	1.8% (1.60-1.96)	1.5% (1.43-1.53)	**0.001**	1.4% (0.82-2.25)	1.7% (1.45-2.01)	0.243
Cesarean section	19.1% (18.58-19.52)*	25.5% (25.36-25.63)	**<0.001**	35.4% (32.95-37.83)*	39.8% (39.03-40.48)	**0.001**
Vaginal breech	0.9% (0.78-1.00)	0.6% (0.56-0.60)	**<0.001**	0.9% (0.46-1.46)	0.4% (0.33-0.53)	**0.014**

∗ Significant difference ($p < 0.05$) between First Nations without diabetes and First Nations with diabetes

poorer outcomes than non-First Nations. Exceptions included age ≥ 35, weight ≤ 45 kg, history of cesarean section, multiple pregnancies, PIH, insufficient weight gain, induction of labour, lower APGAR scores at 5 min, admission to the NICU, and cesarean section, all of which were more common among non-First Nations women. The majority of these differences by ethnicity persisted when comparing only those pregnancies affected by diabetes. Among First Nations women alone, those with diabetes tended to have more pregnancy risk factors and poorer outcomes than those without diabetes. However, anemia, pregnancies ≥ 41 weeks, alcohol consumption, and drug use were less common among those with diabetes than those without diabetes.

Comparisons were also made amongst First Nations women with different types of diabetes in pregnancy (Table 3.4). As opposed to those women with GDM, those with pregestational diabetes were more likely to have antenatal risk factors and adverse infant outcomes. Only inductions of labour and higher mean infant birth weights were more common among women with GDM compared to those with pregestational diabetes.

3.3.2 Prevalence of Diabetes in Pregnancy

Both overall crude and age-adjusted GDM prevalence were significantly elevated for First Nations women in contrast to non-First Nations women, although the First Nations-to-non-First Nations rate ratio was higher after age-adjustment (Table 3.5). First Nations women had higher rates of crude and age-adjusted pregestational diabetes than non-First Nations women (Table 3.5). Age-adjustment resulted in a greater rate ratio between ethnicities.

Table 3.4 Antenatal risk factors and pregnancy outcomes among First Nations women with diabetes in pregnancy (n = 1513) in Alberta, 2000-2009. Values are prevalence per 100 (95% CI) or mean (SD) as appropriate.

	With pregestational diabetes (n = 289)	With GDM (n = 1,224)	p-value
Pregestational			
Age	29.2 (6.03)	28.8 (6.27)	0.407
Age ≤ 17	2.1% (0.77-4.46)	2.9% (2.00-3.96)	0.460
Age ≥ 35	20.1% (15.61-25.16)	20.0% (17.75-22.30)	0.964
Rural	55.4% (49.43-61.18)	51.8% (48.96-54.63)	0.275
Weight ≤ 45 kg	0.7% (0.08-2.48)	0.7% (0.28-1.28)	0.943
Weight ≥ 91 kg	37.0% (31.44-42.87)	30.4% (27.85-33.08)	**0.030**
Hypertension	9.3% (6.25-13.30)	3.0% (2.14-4.14)	**<0.001**
Chronic renal disease	0.7% (0.08-2.48)	0.3% (0.05-0.71)	0.234
Diabetes retinopathy	1.7% (0.56-3.99)	0.1% (0.00-0.45)	**<0.001**
Past obstetrical history			
Parity	2.2 (1.89)	2.2 (2.15)	0.892
Preterm	18.9% (14.40-24.20)	11.2% (9.30-13.33)	**0.001**
Neonatal death	2.4% (0.98-4.93)	1.5% (0.87-2.31)	0.254
Stillbirth	8.0% (5.11-11.70)	4.3% (3.19-5.53)	**0.009**
Abortion	13.1% (9.48-17.60)	8.1% (6.62-9.76)	**0.007**
Cesarean section	25.3% (20.54-30.68)	19.0% (16.87-21.35)	**0.018**
SGA	0.3% (0.00-1.91)	0.2% (0.05-0.71)	0.764
LGA	9.3% (6.25-13.30)	6.4% (5.07-7.89)	0.074
Major fetal anomaly	1.4% (0.38-3.51)	1.1% (0.57-1.81)	0.640
Problems in current pregnancy			
Multiple pregnancy	3.5% (1.67-6.27)	3.5% (2.55-4.70)	0.965
PIH	10.0% (6.82-14.09)	11.3% (9.56-13.18)	0.545
Proteinuria	7.6% (4.83-11.30)	5.2% (3.98-6.54)	0.102
Insufficient weight gain	0.7% (0.08-2.48)	1.6% (1.00-2.51)	0.229
Anemia	0.7% (0.08-2.48)	1.5% (0.87-2.31)	0.297
Pregnancy ≥ 41 weeks	4.5% (2.42-7.57)	5.2% (4.06-6.64)	0.605
Smoker	48.1% (42.21-54.02)	49.7% (46.83-52.51)	0.630

Table 3.4 (continued)

	With pregestational diabetes (n = 289)	With GDM (n = 1224)	p-value
Alcohol ≥ 1 drink per day	1.0% (0.22-3.02)	0.5% (0.18-1.09)	0.285
Alcohol ≥ 3 drinks ever	5.9% (3.49-9.31)	7.4% (5.97-8.99)	0.353
Drug dependant	4.9% (2.69-8.05)	3.2% (2.25-4.32)	0.155
Antepartum risk score	7.1 (4.30)	5.2 (3.25)	**<0.001**
High antepartum risk (≥ 7)	47.1% (41.19-52.99)	26.9% (24.41-29.46)	**<0.001**
Labour and newborn outcomes			
Induction of labour	33.6% (28.14-39.33)	43.6% (40.83-46.46)	**0.002**
APGAR 1 min	7.2 (2.35)	7.6 (1.99)	**<0.001**
APGAR 5 min	8.4 (1.91)	8.7 (8.66)	**0.003**
Birth weight	3490.3 (873.51)	3598.2 (787.34)	**0.041**
LBW	9.0% (5.96-12.90)	6.8% (5.45-8.35)	0.193
HBW	26.3% (21.32-31.77)	30.0% (27.39-32.61)	0.220
Gestational age	37.3 (3.46)	38.0 (2.40)	**<0.001**
Breastfeeding	77.5% (61.55-89.16)	74.2% (68.34-79.49)	0.656
Preterm	22.8% (18.13-28.12)	16.0% (13.96-18.15)	**0.005**
Stillbirth	3.8% (1.92-6.71)	1.7% (1.07-2.61)	**0.027**
NICU admission	19.0% (14.62-24.07)	16.1% (14.08-18.31)	0.326
Congenital anomaly	3.1% (1.36-6.06)	0.9% (0.43-1.79)	**0.032**
Cesarean section	46.7% (40.85-52.65)	32.7% (30.06-35.39)	**<0.001**
Vaginal breech	0.7% (0.08-2.48)	0.9% (0.45-1.60)	0.732

Table 3.5 Crude and age-adjusted prevalence of GDM and pregestational diabetes for all years (n = 427,058) and most recent year of data (2009; n = 51,231) by ethnicity in Alberta. Values are prevalence per 100 (95% CI).

	First Nations	Non-First Nations	Rate ratio*	p-value
Crude				
GDM (all years)	4.3% (4.26-4.38)	3.8% (3.77-3.89)	1.1	**< 0.001**
GDM (2009)	4.9% (4.16-4.63)	4.8% (4.60-4.98)	1.0	0.861
Pregestational diabetes (all years)	1.0% (1.01-1.03)	0.6% (0.58-0.62)	1.7	**< 0.001**
Pregestational diabetes (2009)	1.1% (0.76-1.49)	0.7% (0.60-0.75)	1.6	**< 0.001**
Age-adjusted				
GDM (all years)	6.1% (5.99-6.13)	3.8% (3.74-3.85)	1.6	**< 0.001**
GDM (2009)	6.9% (6.79-6.94)	4.6% (4.58-4.70)	1.5	**< 0.001**
Pregestational diabetes (all years)	1.5% (1.43-1.50)	0.6% (0.57-0.62)	2.5	**< 0.001**
Pregestational diabetes (2009)	1.4% (1.33-1.39)	0.7% (0.64-0.71)	2.0	**< 0.001**

* First Nations-to-non-First Nations

Between 2000 and 2009, age-adjusted prevalence rates of GDM increased significantly only among non-First Nations women (Table 3.6 and Figure 3.1). Prevalence of pregestational diabetes did not increase longitudinally among either First Nations or non-First Nations women, and no between group differences (parallelism) were noted (Figure 3.2 and Table 3.6).

Figures 3.3 and 3.4 show the age-specific prevalence rates by ethnicity over the entire time period for GDM and pregestational diabetes respectively. GDM rates were lowest for both groups among those aged 15-19 years, and increased with increasing age thereafter. Pregestational diabetes rose dramatically among First Nations women aged 30-34 years and 35-39 years, consistent with early onset type 2 diabetes.

Figure 3.1 Age-adjusted prevalence of GDM in pregnancy by ethnicity in Alberta, 2000-2009.

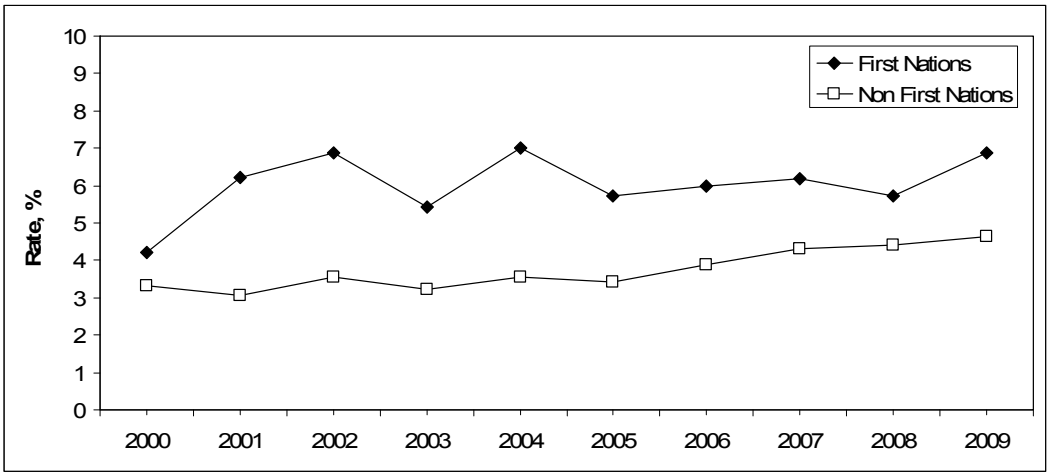


Figure 3.2 Age-adjusted prevalence of pregestational diabetes in pregnancy by ethnicity in Alberta, 2000-2009.

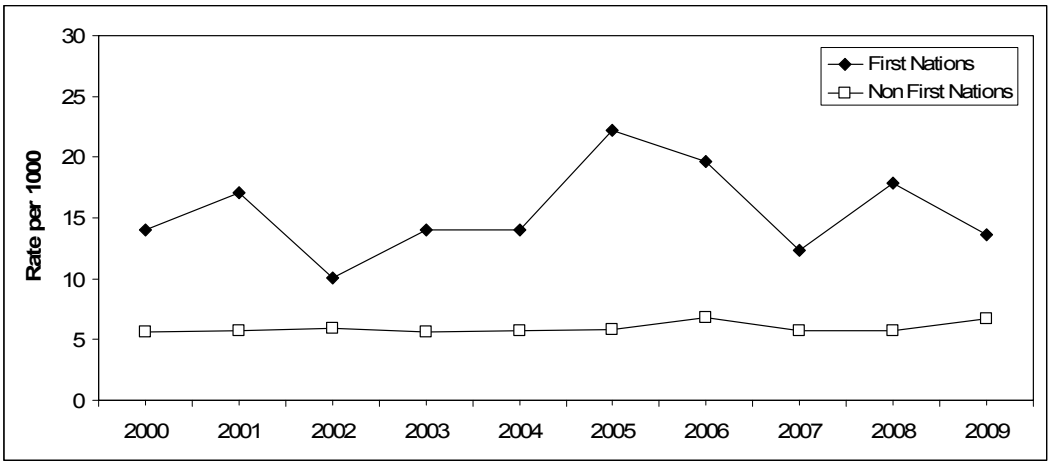


Table 3.6 Ethnicity comparisons of GDM and pregestational diabetes prevalence over time in Alberta, 2000-2009. Values are AAPC (95% CI) in age-adjusted rates.

	First Nations	Non-First Nations
GDM	1.51 (-2.04-5.20)	4.48*† (2.88-6.11)
Pregestational diabetes	1.55 (-4.68-8.19)	1.35 (-0.38-3.12)

* $p < 0.05$ for AAPC

† $p < 0.05$ for difference in AAPC between ethnicities

Figure 3.3 Overall age-specific prevalence of GDM in pregnancy by ethnicity and age group in Alberta.

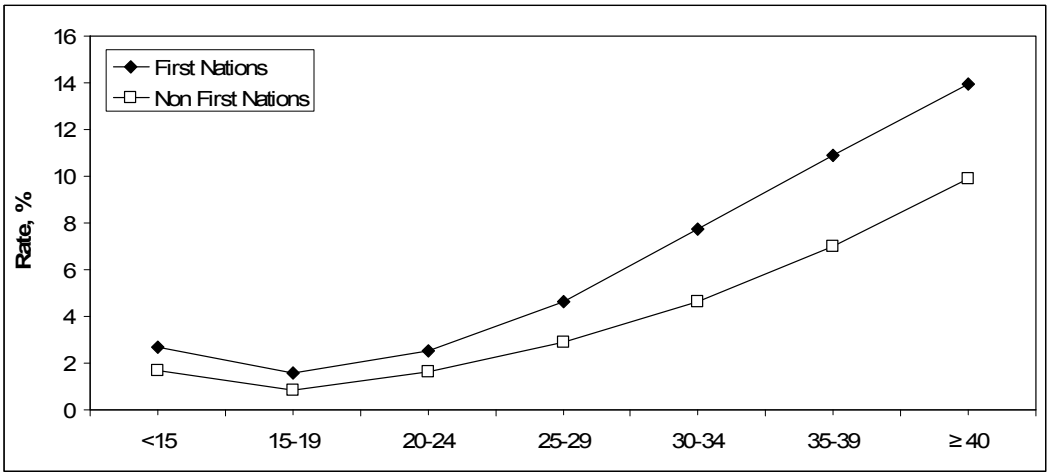
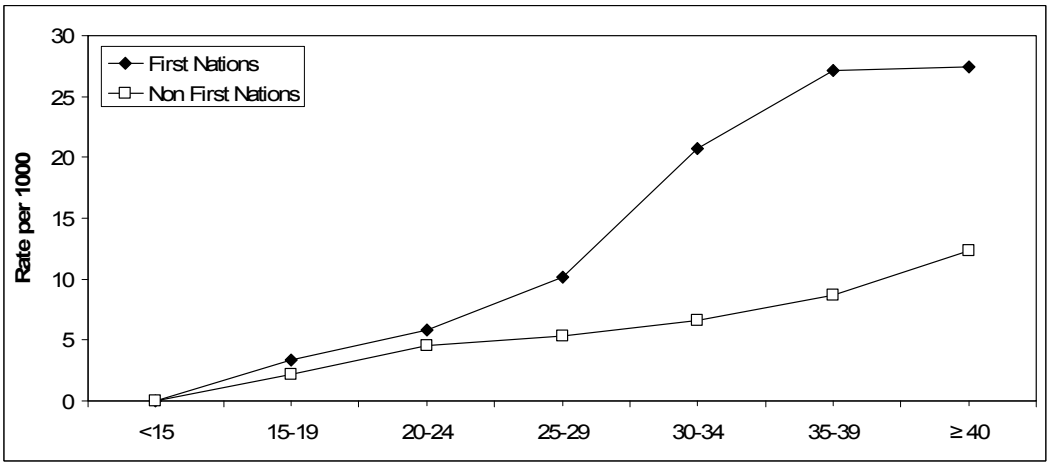


Figure 3.4 Overall age-specific prevalence of pregestational diabetes in pregnancy by ethnicity and age group in Alberta.



3.3.3 Predictors of Diabetes in Pregnancy

The final adjusted logistic regression models with odds ratios (OR) are presented in Table 3.7 and Table 3.8. Among all women, significant predictors of GDM included First Nations ethnicity, age ≥ 35, weight ≥ 91 kg, pregestational hypertension, history of stillbirth, history of cesarean section, and proteinuria. Age ≤ 17, rural residence, smoking, and drug dependence were associated with a

lower risk of GDM. Among First Nations women specifically, significant associations with increased GDM risk were present for age ≥ 35, weight ≥ 91 kg, history of stillbirth, history of cesarean section, history of LGA, and proteinuria. Those age ≤ 17 and with drug dependence had a lower risk of GDM.

Among all women, significant risk factors for pregestational diabetes included First Nations ethnicity, age ≥ 35, weight ≥ 91 kg, pregestational hypertension, history of stillbirth, history of abortion, history of cesarean section, history of LGA, and proteinuria. Age ≤ 17, having a previous SGA infant and alcohol consumption during pregnancy were associated with a lower risk of pregestational diabetes. Among First Nations women specifically, significant predictors of pregestational diabetes included age ≥ 35, weight ≥ 91 kg, history of stillbirth, history of abortion, history of cesarean section, history of LGA infant, and proteinuria. Being at an age ≤ 17 conferred a lower risk of pregestational diabetes.

Table 3.7 Multivariate predictors of GDM among Albertan women by ethnicity. Values are ORs (95% CI).

	All women (n = 427,058)		First Nations (n = 28,306)	
Variable	Multivariate OR (95% CI)	p-value	Multivariate OR (95% CI)	p-value
First Nations ethnicity	1.47 (1.38-1.57)	**<0.001**	--	--
Rural residence	0.69 (0.66-0.73)	**<0.001**	--	--
Age ≤ 17*	0.35 (0.28-0.45)	**<0.001**	0.48 (0.34-0.67)	**<0.001**
Age ≥ 35*	2.34 (2.26-2.42)	**<0.001**	2.81 (2.41-3.27)	**<0.001**
Weight ≥ 91 kg	2.51 (2.40-2.61)	**<0.001**	2.93 (2.56-3.33)	**<0.001**
Hypertension	1.63 (1.45-1.84)	**<0.001**	--	--
History of stillbirth	1.96 (1.75-2.18)	**<0.001**	1.76 (1.30-2.38)	**0.006**

Table 3.7 (continued)				
History of cesarean section	1.37 (1.32-1.43)	**<0.001**	1.40 (1.20-1.63)	**0.001**
History of LGA	--	--	2.58 (1.99-3.35)	**<0.001**
Proteinuria	1.61 (1.48-1.76)	**<0.001**	1.85 (1.40-2.44)	**<0.001**
Smoker	0.90 (0.86-0.94)	**<0.001**	--	--
Drug dependant	0.51 (0.41-0.63)	**<0.001**	0.54 (0.39-0.74)	**<0.001**

∗ Compared to age 18-34

Table 3.8 Multivariate predictors of pregestational diabetes in pregnancy among Albertan women by ethnicity. Values are ORs (95% CI).

	All women (n = 427,058)		First Nations (n = 28,306)	
Variable	Multivariate OR (95% CI)	p-value	Multivariate OR (95% CI)	p-value
First Nations ethnicity	1.73 (1.52-1.96)	**<0.001**	--	--
Age ≤ 17∗	0.29 (0.16-0.52)	**0.001**	0.42 (0.18-0.94)	**0.035**
Age ≥ 35∗	1.57 (1.43-1.72)	**<0.001**	2.23 (1.64-3.02)	**<0.001**
Weight ≥ 91 kg	2.31 (2.10-2.54)	**<0.001**	3.25 (2.52-4.18)	**<0.001**
Hypertension	4.45 (3.82-5.43)	**<0.001**	5.09 (3.03-8.58)	**<0.001**
History of stillbirth	2.56 (2.07-3.18)	**<0.001**	3.05 (1.93-4.81)	**<0.001**
History of abortion	1.42 (1.23-1.64)	**<0.001**	1.58 (1.11-2.25)	**0.035**
History of cesarean section	1.76 (1.61-1.94)	**<0.001**	1.88 (1.41-2.47)	**0.001**
History of SGA	0.53 (0.29-0.96)	**0.038**	--	--
History of LGA	2.79 (2.31-3.39)	**<0.001**	3.23 (2.10-4.97)	**<0.001**
Proteinuria	2.62 (2.23-3.08)	**<0.001**	2.05 (1.26-3.32)	**0.003**
Alcohol anytime	0.68 (0.50-0.93)	**0.016**	--	--

∗ Compared to age 18-34

3.4 Discussion

In this large cohort of pregnancies, several key findings were evident. First Nations women, regardless of diabetes status, were more likely to have antenatal

risk factors and adverse infant outcomes. Having diabetes in pregnancy, particularly pregestational diabetes, compounded these risks and outcomes. Although GDM rates were disproportionately higher among First Nations women, prevalence is growing more rapidly among non-First Nations women. The longitudinal prevalence rates of pregestational diabetes in pregnancy are generally stable, yet First Nations women suffer a greater than two-fold higher prevalence, almost surely due to their early onset of type 2 diabetes, in their twenties and thirties, which are the prime child-bearing years (6). Finally, being of First Nations descent was an independent predictor of both GDM and pregestational diabetes in pregnancy.

Though there are some reports on specific First Nations pregnancy outcomes, little comprehensive data is available as prenatal records and birth registrations tend not to include ethnicity identifiers. This study presents novel data on numerous risk factors and outcomes over ten years on 28,306 First Nations pregnancies in Alberta. Despite comprising only 3.1% of the Alberta female population (18), 6.6% of pregnancies occurred amongst First Nations women. First Nations women also had higher mean values for parity. This suggests fertility/birth rates are higher among First Nations women (19).

First Nations women generally tended to have more adverse pregnancy risk factors and outcomes. This was indicated most clearly via total antenatal risk scores, as the proportion of women without diabetes with a high total score was two-fold higher among First Nations women (10.4%) compared to non-First Nations women (5.1%). Several components of the total antenatal risk score have

been shown to be higher in other First Nations populations outside of Alberta including preterm birth (20), smoking during pregnancy (21), fetal illicit drug exposure (22), and stillbirth (23), all of which were also more common among First Nations women in the current analysis. Pregnancy risk factors that showed the highest disparity between First Nations and non-First Nations women included smoking (3.2 fold), anemia (3.8 fold), alcohol ≥ 3 drinks on any one occasion (5.9 fold), and drug dependency (7.3 fold). It is likely that these factors contributed to the poorer observed outcomes among First Nations infants and interventions are clearly required to mitigate these risks. It is important to notice that First Nations women were less likely to be underweight, have insufficient weight gain, have PIH, or have their pregnancy last ≥ 41 weeks.

The ethnic inequalities in adverse pregnancy risk factors and outcomes persisted when examining only women who had diabetes. This is indicated again by an increased proportion of high total antenatal risk scores among First Nations women (30.7%) than non-First Nations (19.8%). Recently, Liu et al (9) compared some selected pregnancy outcomes among women with diabetes in Ontario and found, among First Nations vs. non-First Nations, significantly higher rates of preterm delivery (12.7% vs. 11.9%) and mean birth weights (3850 g vs. 3343 g). This is consistent with the present analysis. Liu et al (9) however did not find any ethnic differences in NICU admission or cesarean section rates, both of which were lower among Alberta First Nations women. This may reflect regional variation in medical practice. To my knowledge this is the first study to show differences by First Nations status among women with diabetes in high

pregestational weight, pregestational hypertension, chronic renal disease and proteinuria, number of previous pregnancies, anemia, lower APGAR scores, lower gestational age, stillbirth, lower breastfeeding rates, smoking, alcohol consumption, and drug dependency, all of which were significantly more common among First Nations women. Clearly, these statistics call for urgent action to improve preconception and pregnancy care.

This is the first study to compare risk factors and pregnancy outcomes by diabetes status among First Nations women. It was clear that having diabetes increased the risk of several adverse pregnancy risk factors and outcomes. Having pregestational diabetes especially was more detrimental than having GDM among First Nations women as lower APGAR scores, lower gestational ages, as well as higher rates of preterm delivery, stillbirth, cesarean section and congenital anomalies were observed. This is consistent with data among non-Aboriginal women (24).

This study confirms previous reports of higher rates of GDM among First Nations compared to non-First Nations women (10-13). Yet, crude First Nations GDM prevalence in Alberta (4.3%) was lower than that suggested via self-report (10.7%) in Alberta (25), as well as those shown in other parts of Canada such as the Ojibway-Cree of northwestern Ontario (8.4%) and the James Bay Cree in Quebec (8.5%; 12, 26). My data is consistent with the Alberta Diabetes Atlas report of a slightly lower GDM rate of approximately 3.6% for First Nations women using data from Discharge Abstract and Physician Claims databases (27). It is possible that methodological differences in GDM case assessment may be

playing a role in the variation between Alberta rates and those of other provinces, though Aljohani et al (11) utilized a similar method in Manitoba (retrospective provincial-wide prenatal form assessment) and found an overall First Nations GDM prevalence of 6.9%. Provincial inconsistencies are apparent beyond those seen in GDM prevalence among First Nations women alone, as the extent of the difference between ethnicities appears to be less in Alberta. For instance, First Nations-to-non-First Nations rate ratios of GDM prevalence were 1.8 and 2.9 among women in Saskatchewan (10) and Manitoba (11) respectively, as compared to 1.1 (crude) over the entire period of study in Alberta. Interestingly, we have recently shown rate ratios in overall diabetes incidence and prevalence to also be lower in Alberta compared to other provinces (7). Perhaps socioeconomic, clinical practice, or other factors are at play, and clearly future research is needed to uncover explanations.

GDM prevalence is rising in many populations worldwide (28). This is true among non-First Nations Albertan women as well, as a statistically significant growth in GDM over ten years was observed in the current analysis. Increasing age of pregnant non-First Nations women and an influx of minority immigrants likely have contributed to this increase in prevalence (11, 29-31). The story does not seem as clear-cut among Aboriginal populations. While the overall prevalence of GDM was elevated in Alberta First Nations women, rates are not increasing significantly over time. This is consistent with our report on overall diabetes rates in Alberta (7), showing diabetes prevalence is rising more rapidly among the non-First Nations population compared to the First Nations population.

In contrast however, a recent report from Health Canada suggests that 'complications of diabetes in pregnancy' have increased by 149% among First Nations women in Alberta from 2001-2011 (19). The lack of rigorous statistical analysis in the Health Canada report likely accounts for the discrepancy with the findings in the current study. Aljohani et al (11) found GDM prevalence to be increasing over time for all Manitoban women, but unfortunately ethnic-specific trends were not reported. One American study showed GDM prevalence grew among American Indian women from 3.1 to 4.1% over the years 1989-2000 (32). However, studies among Aborigines in Australia have found rates to be either stable (33) or even decreasing (34) over time.

When considering pregestational diabetes in pregnancy prevalence, little is known. Liu et al (9) showed higher rates in Ontario First Nations women (3.9%) compared to their non-First Nations counterparts (1.8%). As with GDM, pregestational diabetes prevalence is lower among Alberta First Nations (1.0% crude; 1.5% age-adjusted) compared to those observed in Ontario First Nations women. To my knowledge this is the first study to describe longitudinal trends of pregestational diabetes in pregnancy in an Aboriginal population. The stability of rates in both the First Nations and non-First Nations populations is both surprising and encouraging as rates of pregestational diabetes in pregnancy are increasing worldwide (35) and overall diabetes rates appear to be increasing in both First Nations and non-First Nations populations (7). However, given the observed elevated prevalence of adverse pregnancy outcomes in women with pregestational diabetes and the lower age of onset of pregestational diabetes among First Nations

women, the 2.5-fold higher prevalence among First Nations women cannot be taken lightly.

It must be noted that the current study was the first to calculate age-adjusted GDM and pregestational diabetes prevalence among a First Nations population. Since advancing maternal age is a risk factor for GDM (3) and the First Nations population is largely young (18), one would expect previous reports are underestimating differences between First Nations and general populations. Case in point, First Nations-to-non-First Nations rate ratios of GDM and pregestational diabetes rose from 1.1 to 1.6 and 1.7 to 2.5 after age-adjustment respectively in the current study. Certainly one must use caution when comparing diabetes in pregnancy rates across studies depending on the methodologies utilized.

Several studies have examined potential predictors of GDM among First Nations women (10, 11, 26, 36), which taken together suggest increasing age, increasing pregestational body mass index, Aboriginal ethnicity, previous GDM, and family history of diabetes are risk factors for GDM. In the current analysis increasing age, elevated pregestational weight and First Nations ethnicity were confirmed as independent predictors for GDM. This study also suggests that in addition to these risk factors, a history of stillbirth, history of cesarean section, history of LGA infant, and the presence of proteinuria are also independent novel predictors of GDM among First Nations women. Moreover, First Nations women that were drug dependent had a significantly less risk of developing GDM. Predictors of pregestational diabetes in pregnancy have not been previously

explored in Canadian Aboriginal women. Among Australian women, increasing weight, pregestational hypertension and proteinuria have been associated with pregestational diabetes (37). These risk factors were evident in First Nations Alberta women, as were history of stillbirth, history of abortion, and history of LGA infant. Importantly, First Nations ethnicity was also shown to be an independent predictor of pregestational diabetes.

There are several limitations to this study. The results cannot be generalized to non-registered Aboriginal or Métis individuals, who could not be identified and were included in the non-First Nations population group. It is likely that some pregestational diabetes was missed in the First Nations women, with two potential consequences. Missed type 2 diabetes, which should have been recognized by history or testing in the first trimester in women with two or more risk factors (more common in Aboriginal women), would be later classified as GDM. More importantly, regardless of classification, delay in treatment of type 2 diabetes from lack of recognition, could have affected outcomes adversely. Whether recognized pregestational diabetes cases were type 1 diabetes or type 2 diabetes could not be discerned from the administrative data, but it has been suggested that in Alberta youth, type 2 diabetes in First Nations is at least as common as type 1 diabetes in the general population (38). The contribution of other potential contextual predictors to the logistic regression models such as socioeconomic status, healthcare access, lifestyle, social environment, gestational weight gain, etc. could not be assessed.

In summary, although First Nations women suffer higher rates of diabetes in pregnancy and more adverse pregnancy outcomes, the epidemiological profile is not as severe as it may be in other Aboriginal populations in Canada. Future studies are needed to uncover reasons for regional variations and should utilize age-adjustments for more informative comparisons across ethnic groups. Clearly Aboriginal groups cannot be 'lumped' together as substantial differences in diabetes in pregnancy exist. As high-risk pregnancies and poor outcomes are more common among First Nations women regardless of diabetes status, efforts must be made to improve pregnancy care in this population. In addition to First Nations ethnicity and previously identified risk factors, pregestational hypertension, a history of stillbirth, history of cesarean section, history of abortion, history of LGA infant, the presence of proteinuria, and drug use during pregnancy may help better identify First Nations women at high risk for diabetes in pregnancy.

3.5 References

1. Kim C, Newton KM, Knopp RH. Gestational diabetes and the incidence of type 2 diabetes: a systematic review. Diabetes Care. 2002;25(10):1862-8.

2. Philipps LH, Santhakumaran S, Gale C, Prior E, Logan KM, Hyde MJ, et al. The diabetic pregnancy and offspring BMI in childhood: a systematic review and meta-analysis. Diabetologia. 2011;54(8):1957-66.

3. Damm P. Future risk of diabetes in mother and child after gestational diabetes mellitus. Int J Gynaecol Obstet. 2009;104 Suppl 1:S25-6.

4. Osgood ND, Dyck RF, Grassmann WK. The inter- and intragenerational impact of gestational diabetes on the epidemic of type 2 diabetes. Am J Public Health. 2011;101(1):173-9.

5. Young TK, Reading J, Elias B, O'Neil JD. Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. CMAJ. 2000;163(5):561-6.

6. Dyck R, Osgood N, Lin TH, Gao A, Stang MR. Epidemiology of diabetes mellitus among First Nations and non-First Nations adults. CMAJ. 2010;182(3):249-56.

7. Oster RT, Johnson JA, Hemmelgarn BR, King M, Balko SU, Svenson LW, et al. Recent epidemiologic trends of diabetes mellitus among status Aboriginal adults. CMAJ. 2011;183(12):E803-8.

8. Willows ND, Sanou D, Bell RC. Assessment of Canadian Cree infants' birth size using the WHO Child Growth Standards. Am J Hum Biol. 2011;23(1):126-31.

9. Liu SL, Shah BR, Naqshbandi M, Tran V, Harris SB. Increased rates of adverse outcomes for gestational diabetes and pre-pregnancy diabetes in on-reserve First Nations women in Ontario, Canada. Diabet Med. 2012;29(8):e180-3.

10. Dyck R, Klomp H, Tan LK, Turnell RW, Boctor MA. A comparison of rates, risk factors, and outcomes of gestational diabetes between Aboriginal and non-Aboriginal women in the Saskatoon health district. Diabetes Care. 2002;25(3):487-93.

11. Aljohani N, Rempel BM, Ludwig S, Morris M, McQuillen K, Cheang M, et al. Gestational diabetes in Manitoba during a twenty-year period. Clin Invest Med. 2008;31(3):E131-7.

12. Godwin M, Muirhead M, Huynh J, Helt B, Grimmer J, Godwin M, et al. Prevalence of gestational diabetes mellitus among Swampy Cree women in Moose Factory, James Bay. CMAJ. 1999;160(9):1299-302.

13. Mohamed N, Dooley J. Gestational diabetes and subsequent development of NIDDM in Aboriginal women of northwestern Ontario. Int J Circumpolar Health. 1998;57(Suppl 1):355-8.

14. Young TK, Martens PJ, Taback SP, Sellers EA, Dean HJ, Cheang M, et al. Type 2 diabetes mellitus in children: prenatal and early infancy risk factors among Native Canadians. Arch Pediatr Adolesc Med. 2002;156(7):651-5.

15. Dyck RF, Tan L, Hoeppner VH. Short report: body mass index, gestational diabetes and diabetes mellitus in three northern Saskatchewan Aboriginal communities. Chronic Dis Can. 1995;16(1):24-6.

16. Dubois L, Girard M. Early determinants of overweight at 4.5 years in a population-based longitudinal study. Int J Obesity. 2006;30:610-7.

17. Statistics Canada. Pregnancy outcomes by age group. 2005. Retrieved online [November 2012] at: http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/hlth65a-eng.htm.

18. Statistics Canada. Aboriginal peoples in Canada in 2006: 2006 census. Ottawa, ON: Statistics Canada; 2006.

19. Yacoub WR. First Nations health status report - Alberta region 2011-12. Ottawa, ON: Health Canada; 2013.

20. Auger N, Fon Sing M, Park AL, Lo E, Trempe N, Luo ZC. Preterm birth in the Inuit and First Nations populations of Québec, Canada, 1981-2008. Int J Circumpolar Health. 2012;71:17520. Epub ahead of print.

21. Wenman WM, Joffres MR, Tataryn IV, Edmonton Perinatal Infections Group. A prospective cohort study of pregnancy risk factors and birth outcomes in Aboriginal women. CMAJ. 2004;171(6):585-9.

22. Kelly L, Dooley J, Cromarty H, Minty B, Morgan A, Madden S, et al. Narcotic-exposed neonates in a First Nations population in northwestern Ontario: incidence and implications. Can Fam Physician. 2011;57(11):e441-7.

23. Simonet F, Wilkins R, Luo ZC. Temporal trends in Inuit, First Nations and non-Aboriginal birth outcomes in rural and northern Quebec. Int J Circumpolar Health. 2012;71. doi:10.3402/ijch.v 71i0.18791.

24. Temple R, Murphy H. Type 2 diabetes in pregnancy: an increasing problem. Best Pract Res Clin Endocrinol Metab. 2010;24(4):591-603.

25. Oster RT, Luyckx VA, Toth EL. Birth weight predicts both proteinuria and overweight/obesity in a rural population of Aboriginal and non-Aboriginal Canadians. J Dev Orig Health Dis. 2013; doi:10.1017/S2040174412000724.

26. Harris SB, Caulfield LE, Sugamori ME, Whalen EA, Henning B. The epidemiology of diabetes in pregnant Native Canadians. A risk profile. Diabetes Care. 1997;20(9):1422-5.

27. Kaul P, Johnson JA, Ryan EA, Chik CL. Chapter 12. Gestational diabetes in Alberta. In Alberta Diabetes Atlas 2011. Edmonton, AB: Institute of Health Economics; 2011.

28. Hunt KJ, Schuller KL. The increasing prevalence of diabetes in pregnancy. Obstet Gynecol Clin North Am. 2007;34(2):173-99.

29. Statistics Canada. Population growth in Canada: from 1851 to 2061. Population and dwelling counts, 2011 census. Ottawa, ON: Statistics Canada; 2011.

30. Alberta Reproductive Health Report Working Group. Alberta reproductive health: pregnancies and births table update 2011. Edmonton, AB: Alberta Health and Wellness; 2011.

31. Urquia M, Glazier RH, Berger H, Ying I, De Souza L, Ray JG. Gestational diabetes among immigrant women. Epidemiology. 2011;22(6):879-80.

32. Moum KR, Holzman GS, Harwell TS, Parsons SL, Adams SD, Oser CS, et al. Increasing rate of diabetes in pregnancy among American Indian and white mothers in Montana and North Dakota, 1989-2000. Matern Child Health J. 2004;8:71-6.

33. Ishak M, Petocz P. Gestational diabetes among Aboriginal Australians: prevalence, time trend, and comparisons with non-Aboriginal Australians. Ethn Dis. 2003;13:55-60.

34. Kim S, Humphrey MD. Decrease in incidence of gestational diabetes mellitus in Far North Queensland between 1992 and 1996. Aust N Z J Obstet Gynaecol. 1999;39:40-3.

35. Feig DS, Palda VA. Type 2 diabetes in pregnancy: a growing concern. Lancet. 2002;359(9318):1690-2.

36. Rodrigues S, Robinson EJ, Ghezzo H, Gray-Donald. Interaction of body weight and ethnicity on risk of gestational diabetes mellitus. Am J Clin Nutr. 1999;70(6):1083-9.

37. Campbell SK, Lynch J, Esterman A, McDermott R. Pre-pregnancy predictors of diabetes in pregnancy among Aboriginal and Torres Strait Islander women in North Queensland, Australia. Matern Child Health J. 2012;16(6):1284-92.

38. Oster RT, Johnson JA, Balko SU, Svenson LW, Toth EL. Increasing rates of diabetes amongst status Aboriginal youth in Alberta, Canada. Int J Circumpolar Health. 2012;71(0):1-7.

CHAPTER 4

The Experiences of Diabetes in Pregnancy among First Nations Women in Alberta; and the Contributors to a Healthy Pregnancy

4.1 Introduction

The current study was aimed at gaining insight into the dramatic differences in rates of diabetes in pregnancy, and outcomes of such pregnancies, between Canadian women of First Nations descent and women of the general population (see chapter 3). In particular, insights from the perspective of First Nations women with real-life experience were sought to gain a deeper understanding in this area, which may ultimately lead to finding appropriate and better ways to help prevent and treat diabetes in pregnancy in First Nations women. Among First Nations women with a history of diabetes in pregnancy the following research questions were explored: 1) what is it like to have diabetes in pregnancy?; and 2) what factors might contribute to attaining a healthy pregnancy complicated by diabetes?

The present-day health of First Nations populations is by and large poorer in comparison with the health of the rest of the Canadian population, at least from a biomedical viewpoint, and type 2 diabetes is no exception (1, 2, 3). In Alberta, diabetes is 2.3 times more common among adult First Nations people (13.5%) than adults of the general population (6.0%; 4). Rates are even higher among other First Nations populations such as those in the First Nations community of Eeyou Istchee, Quebec, where the age-adjusted prevalence of type 2 diabetes was found to be 22.4% among adults (5). Type 2 diabetes in First Nations has been studied extensively from a descriptive and quantitative point of view. Less numerous qualitative studies have suggested that bridging the disconnect between traditional and western views, as well as addressing the cultural and lifestyle

barriers that exist for some First Nations people, are key necessities for type 2 diabetes healthcare moving forward (6-8).

Diabetes in pregnancy, including both gestational diabetes mellitus (GDM) and pregestational diabetes, is increasingly being recognized as a key cyclic contributor to the growing type 2 diabetes epidemic among First Nations (9-11). Diabetes in pregnancy however is only beginning to receive clinical and academic attention. There is an increasing awareness that rates of diabetes in pregnancy and adverse pregnancy outcomes are more common among First Nations women (see chapter 3 and 11-16), but little is known of the experiences of First Nations women with diabetes in pregnancy. Qualitative findings among non-Aboriginal women with GDM (17-21), including a recent review (22), have been published, and suggest areas in need of improvement for the healthcare systems to benefit pregnant women and their families. Many First Nations women experience substantial differences in social, cultural, and physical environments, and possible healthcare improvements that may benefit such women remain unknown. Hence the present study.

4.2 Methods

What is known regarding diabetes in pregnancy in First Nations women has been derived almost exclusively from quantitative epidemiology and clinical studies. To best examine the experience of diabetes and how a healthy pregnancy with diabetes can be reached among First Nations women, this study used ethnography - the study of human cultures. Ethnography is being increasingly

utilized in health research to recognize the context in which beliefs and practices take place, thus helping to understand the behaviours surrounding health (23), and is a fitting method to answer the research questions in this study. Strongly rooted in anthropology, ethnography is a qualitative method used to provide a 'thick description' of a culture's perceptions, patterns of behaviour, shared meanings, values, and assumptions from the perspective of the individuals within the culture (24). Though traditionally grounded in participant observation, modern ethnography utilizes many data collection techniques, including interviewing (23).

Numerous types of ethnographies exist. A focused ethnography differs from a conventional ethnography in that it takes place within a specific context, for a distinct problem, with a specific research question, often to contribute to decision making (23). Due primarily to time constraints the researcher takes on a field-observer role in focused ethnographies instead of a participant role, which is elemental to traditional ethnography (25). Moreover, focused ethnographies typically do not involve participants that know each other or come from the same community; rather they share a similar experience (25). For these reasons, a focused ethnographic approach was used in this study.

4.2.1 Setting

A focused ethnographic qualitative study was conducted in Edmonton, Alberta. First Nations female adult participants resided within Edmonton and/or in surrounding communities.

4.2.2 Sample

Participants were recruited via the practices of two physicians, and the allied health professional members of their diabetes care team, as well as through word of mouth and a recruitment poster (see appendix 2). Participants were approached by the physicians or allied health care professionals who knew them, or called the researcher when recruitment was by word of mouth or posters. First Nations (self-reported) adult women (18 years or older) that had previously had GDM or pregestational diabetes in pregnancy (within five years) were recruited. To be included, participants needed to have received care for diabetes in pregnancy within Edmonton (Alberta). Convenience sampling methodology was utilized whereby participants were selected as they were the only ones available and willing to participate (26).

4.2.3 Data Generation

Data was generated over a period of approximately 10 months from May 2012 to March 2013. Unstructured interviews with participants were carried out at a mutually selected location. During the interviews, open-ended questions were asked by the interviewer to prompt unstructured discussion. Examples of prompting questions included: "What has it been like having diabetes during your pregnancy?", "Tell me about the healthcare you received for your pregnancy. How were your needs met (or unmet)?", "What sort of alternatives (if any) to the mainstream healthcare system did you seek during your pregnancy?", "What sort of 'barriers' did you encounter (if any) to receiving healthcare?" and so on. Interviews were audio recorded and transcribed (verbatim). For participants with

more than one past pregnancy where diabetes was present, interviews focused primarily on the most recent pregnancy.

4.2.4 Data Analysis

All of the data were subject to qualitative content analysis using ATLAS.ti (Berlin, Germany). Data analysis took place concurrently with data collection. To code, interview transcripts were read and re-read, to highlight and identify persistent concepts. Highlighted sections were excised and grouped in categories in separate files. The individual files were re-read and sub-categories were created. After homogeneity was ensured for each, the categories (and sub-categories) were described in-depth. Data collection and analysis ceased upon data saturation, when no new information or insight emerged, and when the categories were well refined and defined. Finally, the categories were considered together, determining if/how they were related and to identify common threads/themes in all of the data.

4.2.5 Rigour

Rather than using a qualitative-specific criteria, strength and rigour were achieved by adhering to the principles of validity, generalizability, and reliability throughout the entire research process as described by Morse et al (27). Such concepts overarch both qualitative and quantitative paradigms (albeit with appropriately different rules), which I believe leads away from segregation of knowledge and ideas. Re-conceptualized for qualitative study, validity refers to assurance that the description of the phenomenon was found in the data, and was ensured through prolonged engagement, collecting and analyzing data concurrently, thinking theoretically to avoid making cognitive leaps, and by a

participant group check after data collection. Generalizability refers to attaining a range of experiences of the phenomenon, and was reached by convenience sampling of women with a broad inclusion criteria and ensuring methodological coherence. Reliability refers to replication and was accomplished via repetition and saturation within the data, as well as completing transcription independently (24, 27). Finally, throughout the entire research process, a reflective approach was strived for by keeping a personal journal of thoughts, emotions, reactions, expectations, assumptions, 'why' questions, etc.

4.2.5 Ethics

Ethical approval was obtained from the Human Research Ethics Board of the University of Alberta. Participants and their communities remained unidentifiable throughout the study, and codes were used as identifiers. An information letter (see appendix 3) detailing the study was reviewed and discussed prior to the first interview, and participants received a copy. Subsequently, written informed consent (see appendix 3) was obtained.

Numerous formal and informal meetings with interested Aboriginal persons were undertaken prior to, during, and after data collection, and served to lend advice, guide the research in a culturally appropriate manner, and to assist with interpretation and dissemination of results. Through these Aboriginal Advisory Group meetings, two key ethical concerns emerged. Firstly, ensuring that the findings benefited the communities that the participants were from was seen as crucial to the ethical integrity of the study. Secondly, preservation of the true and unaltered 'voice' of the participants was seen as necessary to achieve

trustworthy data. To address these concerns, the participants were invited to a group meeting (following data saturation) to hear the results and practical implications identified from the generated data. Attendees had the opportunity to share their views regarding findings, particularly with respect to community benefit and the accuracy of the findings. The participants felt that effective strategies for dissemination of the results to their communities were needed to increase awareness, and this will be undertaken in the intervention/knowledge translation phase of the overall multiphase project (out of scope of the current thesis). Each participant that attended the group meeting was provided their transcript for review and the findings were verified by the participants as an accurate portrayal of their collective experiences.

4.2.6 Study Participants

A total of 12 First Nations participants were needed to reach data saturation. Half of the women self reported having GDM during their most recent pregnancy whereas the other half reported having pregestational type 2 diabetes. The average length of time between the birth of their most recent child and the interview was of three years (range 1-5 years). Participants had an average age of 33 at the time of pregnancy (range 26-39 years) and an average of four children (range 1-6). Although all of the women received some prenatal healthcare within urban Edmonton, nine were from surrounding Aboriginal communities and three lived within Edmonton.

4.3 The Experience of Diabetes in Pregnancy

4.3.1 Challenges: "It was hard"

"Fear", "disappointment", "hassle", "warning", "no control", "it sucked", "I hated it", "scary", "it was hard", "eye-opener", "shocking", "gross", "tough", "annoying", "sickness", "sugar", "tired", "I didn't understand". These are some of the initial words used by participants during the interviews when asked to describe in a few words or less what the term diabetes in pregnancy meant to them. For all of the participants, having diabetes in pregnancy was a difficult experience that took a toll to varying degrees. On top of being pregnant, and all of the demands and challenges a pregnancy presented, the women felt that having diabetes in pregnancy added another layer of "extra work" and "extra stress". As one participant stated, "it was a lot of work. Especially having to take care of your, your whole family on top of that". Another remarked that, "during the whole pregnancy there was just stress for me. It is a lot of stress... Our hormones are out of whack as it is, and then you have high blood sugar to add to that and it's just, it's, it's tough". Most of the women described being exceedingly busy, exhausted, over monitored, and found the increased number of doctor visits and time spent waiting, as well as the added work of managing their diabetes, to be inconvenient and overwhelming. As one participant explained, "I found it problematic to be doing it all the time and testing all the time. You know, and to carry all that stuff around", and continued later stating in reference to doctors' visits that:

> Sometimes I sat there literally for maybe four or five hours. Yeah sometimes I just chose not to go. Just time-wise, I just couldn't see myself sitting there just to see somebody for like ten, fifteen minutes. Waiting three or four hours for like maybe seeing people for about half

> hour altogether... And, that's like half of my day and, especially if you are working or, you know, going to school, that's a lot of time every week.

Every participant conveyed being in a state of fear throughout parts their pregnancy, rooted primarily in fearing for the health and well-being of their fetus. For some, this fear was accompanied by a feeling of shame and self-blame for "not preventing it", "doing something wrong", and ultimately putting their child at "a higher chance of getting diabetes than the other kids". One woman talked about the emotional toll that worrying about her baby took and continues to take on her,

> I won't lie it makes me depressed, thinking about it, worrying about it... Just thinking about the kids having it after it's just, it makes me sad... Scared maybe something, you know like the baby will be born with a disability or missing limbs or something you know? Scared for the baby more than myself. So, I tried to do everything right to make sure nothing happens to the baby. I pray a lot.

Many of the women were also scared for their own health and for the health of their other children, particularly concerning the future risk of diabetes. As one participant described, "I was worried. Yeah, I was actually scared. I didn't want to be a diabetic after I had him. I was scared of all of the sicknesses that comes with it". Complications during the pregnancy and during the birth were also common. Periods of unstable, fluctuating and often high blood sugar levels were experienced by many of the women. Hyperglycemia placed an additional burden for many, as one woman recounted,

> If your sugars are high for long periods of time it brings your emotions down. Like you feel sad, you feel mad, you feel drained. There's so many different emotions that come with high blood sugars. And with pregnancy, it makes it a lot worse... When you have like high blood sugars it makes you feel so low. You don't feel like doing anything at all. You get so lazy. You don't see the world for what it is, like it can be a great place and there are so many things you can do, like you just see it for like this glum place. Like there is nothing to do. You just get bored with your life and the only thing you can run to is food.

4.3.2 Positives: "It helped me too"

Despite the difficulties that accompanied diabetes in pregnancy, each of the women also depicted a positive side to the experience. Having diabetes in pregnancy was a period of time where many of the women felt they were healthier than other times in their lives, including previous pregnancies. Many of the positive aspects centered on lifestyle changes and healthy eating, as one participant explained, "it sounds kind of funny but being diagnosed with diabetes was kind of a good thing for me because that's what I needed to get myself healthier". For some, being diagnosed with diabetes provided the women with their first encounter with a dietitian from whom they learned nutritional concepts that led to healthier eating for both themselves and their families. For instance, for one participant, in comparison to her first pregnancy where she did not have diabetes and was "just eating everything" and subsequently had a "much bigger" baby, she felt improving her eating habits because of having diabetes in her pregnancy led to a healthier outcome for her baby: "when I got pregnant with her

it was different, like she was smaller, like I didn't get as big, and I had to really watch what I ate". For some, having diabetes in pregnancy motivated them to prepare and consume more traditional First Nations foods that they deemed healthier, such as wild meats.

For a lot of the participants these positive lifestyle changes continued after their pregnancy, as indicated by one woman, "it made me take care of myself better and eat healthier. So ever since then me and my kids diet has changed, like a lot. Positive thing, yeah, 'cause still to this day I eat better." And further by another participant,

> But now I know and I can show my kids. I can tell my kids the things that weren't told to me by my grandparents. But I can help them control it before it happens... I'm a different person. I, I try to encourage everybody through everything. Even try and help people when they are feeling bad even if they don't have diabetes. Just like I tried to help myself get through that.

One woman found her health declined post-partum and was subsequently diagnosed with type 2 diabetes. To manage her diabetes and improve her health once again she emulated the lifestyle she adopted during her pregnancy with diabetes,

> I knew I had to do something, so after I had my cry I figured I could either just keep doing what I'm doing, keep gaining weight, or I could do the opposite and go back to the way I ate when I was pregnant. As funny as it sounded that's all I could think of, was eating the way I did when I was pregnant. So I did. So that day I left the doctor's office and I

> changed everything back to what I did when I was pregnant. I started up on the vegetables, I started up on eating three times a day, having my snacks, and then exercising.

The women also described becoming more educated about diabetes in pregnancy, and diabetes in general, after having diabetes in pregnancy, as one woman conveyed, "Now I'm more susceptible to learning and I want to know more". This allowed many of the women to develop into better role models for their families, and in particular for their children, as one participant shared, "so that would probably be the positive effects of it, that I'm more knowledgeable… And um I'm knowledgeable for my kids' sake too, so if any of them ended up with it I would know, like try to be after them".

4.3.3 Control: "A struggle for control"

The concept of control was enmeshed within the experience of diabetes in pregnancy at various levels. As every participant had an extensive family history of diabetes, most of the women felt as if they had little or no control over developing diabetes. Diabetes was expected and there was "no getting around it". One participant said, "my mom has it, my dad has it now, and to be honest it runs in my family. For myself, I knew I was going to get it, it was just a matter of when". The expectation that diabetes is out of their control and is "going to happen to everybody" was seen as a pervasive social norm within the women's communities as well.

A feeling of a loss of control accompanied the diagnosis of diabetes in pregnancy for some of the women. These women felt that having diabetes controlled them as they had to "just do as your doctor says". To keep their

diabetes under control the women had to give up much of their autonomy. Subsequently they felt "forced" to live a changed, unfamiliar, and sometimes unwanted lifestyle. As one participant described,

> Things that aren't in your control anymore. It's always on your mind, and it controls you. You can't do what, you know, whatever you want to do... It's probably for me more a control thing. Now I have to, like I don't want to be told what to do or whatever. Now I'm forced to eat, you know, in a healthy way, and it's hard, hard to take I guess... You really have to be a slave to your, to your eating.

This new compulsory lifestyle was determined in large part by the women's healthcare staff and included a dramatic shift in dietary habits and physical activity patterns, numerous medical appointments, being over-examined, constant blood monitoring, and insulin injections and adjustments, that some of the women felt they had little choice in. When asked to delve deeper into what this new lifestyle entailed one participant responded,

> I felt like I had no control over my health... Well, you got to do everything according to what the doctor and the dietitian say in order to manage it. Otherwise you get all of these problems with your health. So yeah, that kind of control. Like you can't, I guess live comfortably with the pregnancy unless you do as you are told. Follow the directions of taking your insulin on time, eating properly, exercising.

The feeling of loss of control was not all-encompassing, as some of the women viewed following healthcare provider orders as an opportunity to take control of own their health. For instance, one participant stated, "I never really felt

out of control, I always felt that I was doing something that I should be, and trying to follow it to my best ability". When asked whether managing her diabetes felt like a loss of control another woman replied,

> Not really giving up control but to make it stronger I guess you can say, because if you didn't have control then everything would be all over... 'Cause if you don't have control then you don't have anything. So I had to, I had to take control because the control I had prior to pregnancy was I didn't have any.

Much of the notion of control centered on blood sugar levels, and behaviours that influence blood sugar levels including insulin injections, eating habits, and physical activity. Having their blood sugar levels within the accepted range dictated by their doctors was considered the benchmark for having a healthy pregnancy for many of the women. Each woman was faced with "a struggle for control" and did what they could to manage, as one participant recounted, "sometimes I had it under control... I tried my best in my pregnancy." For some, being "faithful" to their healthcare providers and controlling their blood sugar levels was achievable, and often resulted in feelings of satisfaction and fulfillment. On the other hand, keeping their blood sugar levels under control was more difficult for a number of participants which resulted in feelings of failure and unhappiness, as pointed out by one woman,

> My blood sugars got out of control. I knew basically a lot about diabetes, I just couldn't control it... Like, I couldn't control my emotions, I couldn't control my blood sugar, I couldn't control how much I ate, I couldn't control anything. I just felt, I felt helpless.

4.3.4 Summary

Taken together, the experience of diabetes in pregnancy for First Nations women was "good and bad" as one participant voiced, one wrought with struggle but balanced to some degree by positive lifestyle changes. A loss of control, and at the same time striving to control blood sugar levels, permeated living with diabetes in pregnancy. For some women, diabetes in pregnancy offered a chance to take control of their health. The degree to which the women felt they could control their diabetes and their health strongly influenced whether the women felt they had had a positive or a negative pregnancy experience.

4.4 Contributors to Achieving a Healthy Pregnancy

4.4.1 Support: "I didn't do it alone"

Support during their pregnancy was a prevailing theme discussed by the women. Having the positive support and encouragement of their family, be it relatives, children, significant others, mothers, siblings, mothers-in-law, or grandparents, was crucial to a healthy pregnancy. Even the support of only one family member was vital, as revealed by one woman, "just one person having support is really, really helpful. To help you, like encourage you and you know, support you, and kind of walk with you while you are going through it". Negative family support was detrimental to pregnancy health and wellbeing, and "unhealthy" family members were avoided by some of the women. Family support often consisted of "just being there" and taking care of "little things" such as childcare during appointments, food preparation, reminders, someone to talk to,

and household chores. Family support was also essential in the women's ability to sustain the lifestyle changes necessary for diabetes management, as one participant revealed,

> We all did it together. I didn't only do it alone. It was with the help of my family too that made it easier... Family helped, yeah. I had a lot of support because it was one thing for me to change, but I think it's harder to change when you are the only one eating differently and doing this differently and they're still eating chips and still you know going out to eat fast food places. So that was one thing that was really good.

Although the women expressed a real need for help from all family members, spousal support was frequently the most pivotal. In particular, spouses that were encouraging and modeled positive lifestyle changes was a significant motivator for the women to do the same and helped "alleviate a lot of stress." Lack of spousal support led to more challenging and difficult pregnancies, as pointed out by one participant when asked about adopting new dietary patterns,

> My husband tried to understand. Like he tried to help me but he couldn't really fully understand what I was going through because when I was trying to control my diet and trying to control certain things I was eating he was eating them right in front of me... He would try until I gave up, then he would give up. Like he wasn't there telling me I shouldn't be eating that... Like if you don't have that person encouraging you then (you're) gonna feel like, like crap.

Equally important was support from healthcare staff. Those women that described receiving positive, empowering, and validating support depicted less arduous and even pleasant (for some) pregnancies, and felt more optimistic about

their health and their children's health. Healthcare providers that genuinely listened to and worked with their patients, and at the same time provided a 'level playing field' environment where the women felt as equals, allowed for learning to take place and ensuing diabetes management. On the other hand, those women that experienced negative, demanding, fear-inducing, and paternalistic healthcare tended to result in feelings of failure, non-compliance and even backlash, especially when family support was also lacking. Many of these women that felt they did not have a supportive healthcare staff also felt as if they were not listened to. As one participant described,

> The only thing that was hard during the whole pregnancy was the doctors... Because I felt like I was failing all of the time. I felt like ah, I didn't have the support I needed... By the end of the pregnancy, I was pretty much blocking out pretty much what most of the doctors were saying and trying to do what I thought was best... The best thing for people with diabetes, is encouragement. Um, women like to hear like they are doing something good, not just something that they are harming themselves, harming their babies. They want to hear that they're actually accomplishing something... Like from some people I have encountered they're more lecturing you all of the time. They don't understand what you are going through and they, their aggression pretty much does the opposite.

Another source of support was cultural and community support. Some women longed for help from Elders or Medicine Keepers within their communities, not specifically for their diabetes but rather for emotional support

and to fulfill the cultural/spiritual aspect of their health that was missing within the mainstream healthcare system. As one participant said, "it helps just to talk to them and get their experience and stuff like that", and further by another participant,

> To me health is more holistic and not just, you know, what the doctors say. There's so many other things I think. Like, so many different aspects of being a patient rather than you just being, like westernized medicine. There's the whole other spiritual aspect... I would like to say maybe more the cultural understanding. Like, you know, I find, I found that it's very westernized. And you know just would have been cool to have other people share their experiences. Like, being with other Aboriginal people. And you know it would have been cool to have that kind of support, even from an like Elder.

For others this cultural support was more available and already part of their life, as one woman divulged, "I've always pretty much had cultural aspects in my life and um when I thought I needed it I would use the sweet grass, the sage, and smudge myself whenever I was troubled or worried about my health or about the baby or anything."

Cultural and community support also encompassed more, including connections with women experiencing similar situations of diabetes in pregnancy. Relating to other women helped participants feel less alone. For instance, one participant who attended a specific class for women with diabetes in pregnancy felt, "it was like we opened up to each other, even though we never met each other... It was kind of like we were all in there for the same thing. And that was a

big, big help." Connections with the broader community were also sought by most of the women, such as through the sharing of wild meat and traditional foods by some and engaging with friends whom provided "an open ear" by others.

In addition to family, healthcare provider and cultural/community support, all of the women looked internally for support as well, and experienced a powerful responsibility to "put my children first". Having diabetes in pregnancy intensified this obligation as the women knew their growing child was "at a greater risk", which motivated the women to take steps to manage their diabetes. The women felt obligated to eat as healthy as they could, to learn about diabetes, to follow orders, to monitor and manage their blood sugar levels, and to make doctor appointments, all "for my health and for my baby". This internal support also compelled the women to be as healthy as possible not only for their fetus, but for their other children as well, as revealed by one woman, "probably just to like keep me going… Just basically looking at them and thinking well gee I got to try to live as long as I can and give them a good life", and by another,

> My children. My health. The knowing that if I don't do it then, you know, my health could deteriorate and then knowing that if I do follow directions then you know I could manage this. I could possibly even beat it. So yeah the motivation is my kids. Just you know being there for them, being healthy, being a role model for them. So, if I eat healthy and stuff like that, like vegetables, then my kids do.

Several participants sought emotional support during their pregnancy, typically from family members or from cultural and/or community sources. In

cases where such support was unavailable some women looked to the healthcare system. As one woman pointed out,

> There's a lot of issues and stuff that go on during a woman's pregnancy in the nine months... Like I basically had to do it on my own and you can't really do that if you are pregnant and stuff 'cause of all of the emotions and stuff. It was hard... But there wasn't really any emotional support for being pregnant and going through what I was going through. Um I think if, I don't know, I think it would have been better to have some kind of support like that, like even to talk to a counselor or somebody... And a lot of people too, they don't have much family to run to or anything. And for the doctors to offer a support system, or to go and talk to somebody it would be helpful, very helpful.

4.4.2 Awareness and Resources: "There was a lot to learn"

Prior to becoming pregnant, the participants varied in their knowledge of diabetes in pregnancy, but most felt there was a lack of available information from healthcare organizations and a lack of awareness within their communities. Those women that had had GDM rather than pregestational diabetes, especially if they where experiencing it for the first time, tended to be shocked and surprised at being diagnosed. Despite type 2 diabetes being so common within their families and communities, there was much less awareness of diabetes in pregnancy and many of the women "didn't even know what it was". As on woman explained,

> 'Cause I didn't know anything about it... I didn't even know what it was. I was shocked. I was shocked. Yeah, 'cause I know what diabetes is, so then it scared me too... It would help more women out there if there was more information about gestational out there. 'Cause there is still a lot of

> women that don't even know what it is. And I think a lot of it could be prevented if they, if they knew about it like right away or in the beginning of their pregnancy. Yeah, then maybe they wouldn't get it.

Once diagnosed with diabetes in pregnancy, many of the women felt "there was a lot to learn" and were subsequently overwhelmed with the amount information that was provided to them in a short period of time by their healthcare providers. On top of this, some also felt that the information was confusing and too complicated, as one participant reflected,

> It was just a whole lot of information thrown at me and then I go home and I supposed to remember how to do this, when to do this, when to do that, how much of this, and it was overwhelming... We had a dietitian come in and talk to us about what we should and shouldn't be eating. That was really again a whole lot of information. Like "slow down, I don't know what you are talking about. And I don't know how to read this. I don't know how to read, you know, the labels on the food. And is this good? Is this not good?"... And she's adding up all of these things and it's coming up to a number, and I'm like "I don't know <*laughter*> I don't know how to do that." So that was confusing.

Alternatively some of the women, particularly those that worked in healthcare fields or those who had already lived with diabetes for numerous years, felt very knowledgeable about diabetes in pregnancy and had an easier time grasping and adjusting to the diabetes regimen. Many took it upon themselves to do their own research to educate themselves on diabetes in pregnancy via internet searches and books.

Other than prior awareness and knowledge of diabetes in pregnancy, overall the women felt they had the necessary tangible resources to manage their diabetes. For instance, the majority of the women described having good access to the healthcare system, including both those services in their immediate community as well as those within Edmonton. Most had no difficulty travelling to the city for care either by themselves or by utilizing community health center transportation services. However, having to pay for gas and parking was problematic for some participants. Similarly, most felt they had good access to healthy food where they lived, but a few of the women found eating healthy to be a financial burden. Although options for physical activity were limited in many of the participant's communities, those that described exercising in their pregnancies were creative in using whatever resources they had such as walking, cleaning, or other household chores. When asked about how she stayed active one woman responded,

> Mostly just walking... Just little things to get yourself into exercise... So I would either walk to the grocery store to get my stuff or I would drive to the grocery store, depending on where I was at, and just park far away in the parking lot and walk across and just take my time... Even though if I only had a couple of things to grab and I knew where they were, I'd still walk like the whole aisle of the grocery store trying to get in as much exercise as I could.

4.4.3 Summary

Having a strong support system including family, healthcare provider, cultural/community, and internal support, was crucial to whether First Nations

women with diabetes in pregnancy felt they had a healthy pregnancy or not. Facing diabetes in pregnancy alone resulted in a daunting and challenging pregnancy. Most women had the necessary resources to manage their diabetes but when awareness and preceding knowledge of diabetes in pregnancy was lacking, many of the women felt overwhelmed with information upon diagnosis.

4.5 Discussion

The intention of this study was to understand both the experience of diabetes in pregnancy and the factors that contribute to a healthy pregnancy complicated by diabetes among First Nations women. Based on previous qualitative research with Aboriginal people with type 2 diabetes (6-8) it was anticipated that First Nations women with diabetes in pregnancy would experience a lack of culturally sensitive care and a disconnect between traditional and mainstream healing practices during their pregnancy. It was also anticipated that interconnected social and health problems would preclude appropriate diabetes management and result in overwhelmingly difficult pregnancies (28). Although cultural support was important for some of the women and social barriers were present, these were not prevailing themes. Rather, the findings suggest that having diabetes in pregnancy is both a challenging and a positive experience. The ability to withstand the challenges, maximize the positives, and ultimately reach a state where the women felt they had had a healthy pregnancy, depended on whether the women felt in control of their diabetes. Having supportive and caring relationships during their pregnancies, as well as having

prior knowledge and awareness of diabetes in pregnancy, enhanced the women's capacity to manage their diabetes and have control over their health. Of course the opposite was true, when a lack of support and resources led to poorer diabetes control and a sense of loss of control, and ultimately a more difficult pregnancy experience.

The five widespread themes reported in the current study (Challenges, Positives, Control, Support, and Awareness and Resources) have been shown in the recent upsurge of qualitative work with non-Aboriginal women with previous GDM. For instance, Persson et al (20) showed in their grounded theory work with Swedish women that the experience comprises both positive and negative dimensions and that women look internally for support as fetal health is the primary motivator for diabetes management. Living in a supportive environment was found to catalyze the need to maximize fetal health in Australian women with GDM (29). Evans and O'Brien (17) exposed the concept of control as intrinsic to the experience of having GDM. Among South Asian women in Australia, Bandyopadhyay et al (30) found women's knowledge and awareness of any diabetes was low which resulted in difficulties in taking in the wealth of information upon diagnosis.

The parallels to previous qualitative reports is in-fact a novel finding of the current study. Taken in the context of previous work, this study suggests that despite one's ethnic background the experience of diabetes in pregnancy is often similar, and that diabetes in pregnancy is a complicated problem for all pregnant women. Although their life circumstances and way of life may be different, their

needs during pregnancy with diabetes are often the same. Women with diabetes in pregnancy need robust support systems and the necessary resources (17-22, 29, 30). Because of inequalities in the social determinants of health (1-3) and the continuing intergenerational effects of colonialism (28) it is almost certain that some First Nations women require more support and resources when experiencing diabetes in pregnancy.

Only two other studies have qualitatively examined diabetes in pregnancy in Canadian Aboriginal women, Neufeld (31) and Gaudreau and Michaud (32). Both studies included only women with GDM in their pregnancies. Neufeld focused on dietary perceptions of Aboriginal women in Winnipeg, Manitoba, and found women experiencing overwhelming, frustrating, anxious, and negative pregnancies cumulating with a sense of failure and ineffective diabetes management (31). The article also describes the women living in traumatic life circumstances, being socially isolated, having little knowledge and awareness of diabetes in pregnancy, and having poor relationships with their healthcare providers (31). The women in the current study did encounter struggles, but seemingly not to the same extent and with more support that those in the Neufeld study, and thus unsurprisingly seemed to have less negative experiences overall. The Gaudreau and Michaud (32) article did not focus on the experience of diabetes in pregnancy specifically, but rather on the cultural factors that help Algonquin women (Quebec) maintain healthy behaviours. Nevertheless, their study also indicates that women with diabetes in pregnancy need both support and resources as family and community support were found to be primary motivators.

Cultural support in particular was very important to the Algonquin women, be it through preserving their traditional diet, engaging in a holistic healing approach, and acquiring new knowledge and activities that were culturally adapted (32).

Another novel aspect of this study was the inclusion of women with pregestational type 2 diabetes. The vast majority of qualitative data in this area has been generated among women with GDM or pregestational type 1 diabetes. To my knowledge this is the first study to qualitatively explore pregestational type 2 diabetes in First Nations women. Striking differences between those with GDM and those with pregestational type 2 diabetes were not apparent, except when considering knowledge and awareness of diabetes in pregnancy. Those women with pregestational type 2 diabetes seemed to have a better understanding and knowledge base of diabetes in general than those with GDM. However, this did not necessarily translate to better diabetes management and healthier pregnancies as the women differed in their support systems and subsequent control.

This study provides a strong argument for a more patient-centered approach to diabetes in pregnancy care in First Nations women. Patient-centered care as an idea was originally introduced in the medical literature in the mid 1950s as a better approach compared to illness-centered care (33), and has subsequently gained momentum as a holistic paradigm that identifies and responds to patients' individual identities, knowledge, experiences, lives, and points of view (34). Numerous definitions exist, but that of the U.S. Institute of Medicine is most commonly cited: "providing care that is respectful of and responsive to individual preferences, needs, and values and ensuring that patient

values guide all clinical decisions" (35). A large amount of literature has been published on patient-centered care rationale, types, interventions, and effectiveness. In a recent Cochrane review (36), interventions to promote the transfer of patient-centered care skills to providers were effective across all studies. The effectiveness on patient satisfaction, health behaviour and health status were mixed, yet interventions that were more condition-specific tended to show more positive results (36). For example, a randomized controlled trial found that compared to control "usual care", patient-centered care targeting diabetes specifically significantly reduced hemoglobin A1c levels, as well as increased predicted life expectancy and quality-adjusted life years in patients with type 1 and type 2 diabetes in the Netherlands (37). No studies have examined the effectiveness of a patient-centered care approach to diabetes in pregnancy.

The characteristics of patient-centered care fit well with the contributors to a healthy pregnancy identified by the women in the current study. Patient-centered care allows for the provider to put themselves in the patient's world and see illness through the patients' eyes, and ultimately appreciate the patient as a unique person rather than a disease (34). Likewise, the patient may begin to see the provider as a real person as well (34). Such a model of care may compel the provider to engage more with the patient to become knowledgeable about the woman's ethnicity, culture, personality, life circumstances, etc. (36). Subsequently, the provider can gain more insight into the woman's existing support system and resources, and perhaps find ways to work with patients in order to enhance these components of a healthy pregnancy. Providers must listen

to the patient, which many of the women in the current study either longed for or appreciated (if they had such a relationship with their providers). Essentially, patient-centered care allows for more positive and caring provider support (36), which was a crucial source of support desired by the women in this study. Any decisions that are made would thus be specific to each woman's life. Moreover, patient-centered care requires mutually exchanging of information, shared power and decision making, and an even patient-provider partnership (34-38), all of which could enhance the women's sense of control and autonomy. Control was a prevalent concept in the experience of diabetes in pregnancy and was interpreted in multiple layers by participants, further necessitating the need for providers to share control in the interaction. All of this being said, the patients' preferred level of provider involvement must be appraised initially as each patient is different (36).

There are limitations to this study. The criteria that women had had diabetes in pregnancy within the previous five years could be challenged, although this was done to reach data saturation and to make the findings more generalizable. Moreover, the five year cutoff is comparable to other similar studies (31, 32). The insights garnered are limited to an extent by the inclusion criteria which called for women that received healthcare within Edmonton. The perspectives of women that did not come to the city for care, and those that did not receive prenatal care (which would likely be the most vulnerable) could not be captured.

In summary, every woman's story of having diabetes in pregnancy in this study was unique, yet similar themes were apparent. Diabetes in pregnancy for First Nations women presents many difficulties that are balanced to some degree by positive lifestyle changes. A struggle for control over blood sugar levels, diabetes, and overall health was a continuing theme throughout the pregnancy experience. Having a strong support system (including family, healthcare provider, cultural/community and internal support) as well as the necessary resources (primarily awareness/education of diabetes in pregnancy) allowed women to take some control of their health. First Nations women with diabetes in pregnancy are not likely to benefit from 'broad brush' care from their providers. Efforts to improve pregnancy care should look to enhance the support systems of these women, increase their sense of autonomy, and raise awareness of diabetes in pregnancy and its accompanying challenges. Accordingly, more patient-centered care approach should be strived for when caring for First Nations women with diabetes in pregnancy.

4.6 References

1. Adelson N. The embodiment of inequity: Health disparities in Aboriginal Canada. Can J Public Health. 2005;96(Suppl 2):S45-61.

2. Gracey M, King M. Indigenous health part 1: Determinants and disease patterns. Lancet. 2009;374(9683):65-75.

3. Kmetic A, Reading J, Estey E. Taking a life course perspective on cardiovascular disease and diabetes in First Nations peoples. Can J Nurs Res.

2008;40(3):58-78.

4. Oster RT, Johnson JA, Hemmelgarn BR, King M, Balko SU, Svenson LW, et al. Recent epidemiologic trends of diabetes mellitus among status Aboriginal adults. CMAJ. 2011;183(12):E803-8.

5. Dannenbaum D, Kuzmina E, Lejeune P, Torrie J, Gangbe M. Prevalence of diabetes and diabetes-related complications in First Nations communities in northern Quebec (Eeyou Istchee), Canada. Can J Diabetes. 2008;32(1):46-52.

6. Barton SS, Anderson N, Thommasen HV. The diabetes experiences of Aboriginal people living in a rural Canadian community. Aust J Rural Health. 2005;13(4):242-6.

7. Barton SS. Using narrative inquiry to elicit diabetes self-care experience in an Aboriginal population. Can J Nurs Res. 2008;40(3):16-36.

8. Gregory D, Whalley W, Olson J, Bain M, Harper GG, Roberts L, et al. Exploring the experience of type 2 diabetes in urban Aboriginal people. Can J Nurs Res. 1999;31(1):101-15.

9. Osgood ND, Dyck RF, Grassmann WK. The inter- and intra-generational impact of gestational diabetes on the epidemic of type 2 diabetes. Am J Public Health. 2011;101(1):173-9.

10. Caulfield LE, Harris SB, Whalen EA, Sugamori ME. Maternal nutritional status, diabetes and risk of macrosomia among Native Canadian women. Early Hum Dev. 1998;50(3): 293-303.

11. Liu SL, Shah BR, Naqshbandi M, Tran V, Harris SB. Increased rates of adverse outcomes for gestational diabetes and pre-pregnancy diabetes in on-reserve First Nations women in Ontario, Canada. Diabet Med. 2012;29(8):e180-3.

12 Dyck R, Klomp H, Tan LK, Turnell RW, Boctor MA. A comparison of rates, risk factors, and outcomes of gestational diabetes between Aboriginal and non-Aboriginal women in the Saskatoon health district. Diabetes Care. 2002;25(3):487-93.

13. Rodrigues S, Robinson E, Gray-Donald K. Prevalence of gestational diabetes mellitus among James Bay Cree women in northern Québec. CMAJ. 1999;160(9):1293-7.

14. Godwin M, Muirhead M, Huynh J, Helt B, Grimmer J. Prevalence of gestational diabetes mellitus among Swampy Cree women in Moose Factory, James Bay. CMAJ. 1999;160(9):1299-302.

15. Aljohani N, Rempel BM, Ludwig S, Morris M, McQuillen K, Cheang M, et al. Gestational diabetes in Manitoba during a twenty-year period. Clin Invest Med. 2008;31(3):E131-7.

16. Willows ND, Sanou D, Bell RC. Assessment of Canadian Cree infants' birth size using the WHO Child Growth Standards. Am J Hum Biol. 2011;23(1):126-31.

17. Evans MK, O'Brien B. Gestational diabetes: The meaning of an at-risk pregnancy. Qual Health Res. 2005;15(1):66-81.

18. Hjelm K, Bard K, Nyberg P, Apelqvist J. Management of gestational diabetes from the patient's perspective--a comparison of Swedish and middle-eastern born women. J Clin Nurs. 2007;16(1):168-78.

19. Hjelm K, Bard K, Nyberg P, Apelqvist J. Swedish and middle-eastern-born women's beliefs about gestational diabetes. Midwifery. 2005;21(1):44-60.

20. Persson M, Winkvist A, Mogren I. 'From stun to gradual balance' - women's experiences of living with gestational diabetes mellitus. Scand J Caring Sci. 2009;24(3):454-62.

21. Marquez DX, Bustamante EE, Bock BC, Markenson G, Tovar A, Chasan-Taber L. Perspectives of Latina and non-Latina white women on barriers and facilitators to exercise in pregnancy. Women Health. 2009;49(6):505-21.

22. Devsam BU, Boqossian FE, Peacock AS. An interpretive review of women's experiences of gestational diabetes mellitus: Proposing a framework to enhance midwifery assessment. Women Birth. 2013;pii:S1871-92.

23. Savage J. Ethnography and health care. British Medical Journal (Clinical Research Ed.). 2000;321(7273):1400-2.

24. Mayan MJ. *Essentials of Qualitative Inquir*y. Walnut Creek, CA: Left Coast Press, Inc; 2009.

25. Knoblauch H. Focused ethnography. Forum Qualitative Social Research. 2005;6(3):Article 44.

26. Patton MQ. *Qualitative Evaluation and Research Methods 2nd Edition*. Newbury Park, CA: SAGE Publications; 1990.

27. Morse JM, Barret M, Mayan MJ, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. International Journal of Qualitative Methods. 2002;1(2):13-22.

28. King M, Smith A, Gracey M. Indigenous health part 2: The underlying causes of the health gap. Lancet. 2009;374(9683):76-85.

29. Carolan M, Gill GK, Steele C. Women's experiences of factors that facilitate or inhibit gestational diabetes self-management. BMC Pregnancy Childbirth. 2012:doi:10.1186/1471-2393-12-99.

30. Bandyopadhyay M, Small R, Davey MA, Oats JJ, Forster DA, Aylward A. Lived experience of gestational diabetes mellitus among immigrant South Asian women in Australia. Aust N Z J Obstet Gynaecol. 2011;51(4):360-4.

31. Neufeld HT. Food perceptions and concerns of Aboriginal women coping with gestational diabetes in Winnipeg, Manitoba. J Nutr Educ Behav. 2011;43(6):482-91.

32. Gaudreau S, Michaud C. Cultural factors related to the maintenance of health behaviours in Algonquin women with a history of gestational diabetes. Chronic Dis Inj Can. 2012;32(3):140-8.

33. Balint M. The doctor, his patient, and the illness. Lancet. 1955;265(6866):683-8.

34. Hudon C, Fortin M, Haggerty J, Loignon C, Lambert M, Poitras ME. Patient-centered care in chronic disease management: a thematic analysis of the literature in family medicine. Patient Educ Couns. 2012;88(2):170-6.

35. Committee on Quality of Health Care in America: Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. 2001. Retrieved online [March 2013] at: http://www.iom.edu/Reports/2001/Crossing-the-Quality-Chasm-A-New-Health-System-for-the-21st-Century.aspx.

36. Dwamena F, Holmes-Rovner M, Gaulden CM, Jorgenson S, Sadigh G, Sikorskii A, et al. Interventions for providers to promote a patient-centered approach in clinical consultations. Cochrane Database Syst Rev. 2012;12:12:CD003267.

37. Dijkstra RF, Niessen LW, Braspenning JC, Adang E, Grol RT. Patient-centred and professional-directed implementation strategies for diabetes guidelines: a cluster-randomized trial-based cost-effectiveness analysis. Diabet Med. 2006;23(2):164-70.

38. Williams BJ. The way to patient-centered care. Nurs Manage. 2010;41(10):10-2.

CHAPTER 5

General Discussion and Conclusions

5.1 Overview of Findings

This mixed methods thesis was comprised of two studies aimed to address the following objectives:

1) To use administrative data from the Alberta Perinatal Health Program (APHP) and the Ministry of Alberta Health & Wellness (AHW) to generate an epidemiological profile of First Nations diabetes in pregnancy in Alberta; and

2) To use a focused ethnographic approach to understand the experience of diabetes in pregnancy and what factors could contribute to achieving a healthy pregnancy in First Nations women.

From the epidemiological analysis of provincial delivery records for the years 2000-2009 the following major findings were discerned. Antenatal risk factors and adverse infant outcomes were more common among First Nations women compared to non-First Nations women. Having diabetes in pregnancy, pregestational diabetes more so than gestational diabetes (GDM), increased these risks and outcomes. First Nations women suffered higher prevalence rates of both GDM and pregestational diabetes than non-First Nations women. Longitudinal analyses indicated that GDM prevalence is relatively stable in the First Nations population but growing among non-First Nations women. Prevalence rates of pregestational diabetes in pregnancy were generally constant in both populations. Being of First Nations descent was an independent predictor of both GDM and pregestational diabetes in pregnancy. Also, in addition to age ≥ 35 and weight $\geq$ 91 kg, non-traditional factors including pregestational hypertension, a history of

stillbirth, history of cesarean section, history of abortion, history of large for gestational age infant, the presence of proteinuria, and drug use during pregnancy were associated with diabetes in pregnancy in First Nations women.

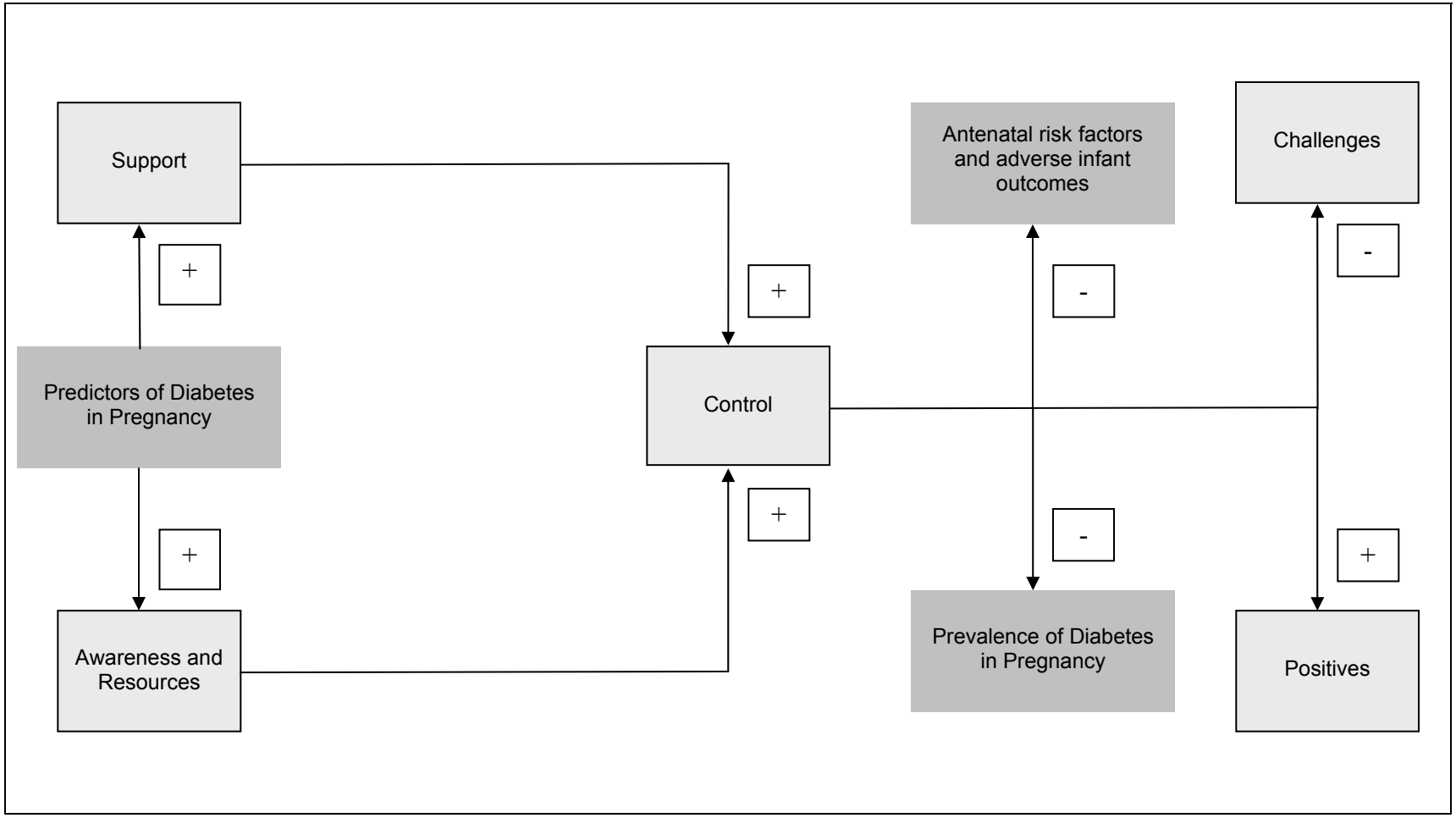
The focused ethnographic analysis generated five themes common to each woman's story: Challenges, Positives, Control, Support, and Awareness and Resources. Diabetes in pregnancy presented many challenges for First Nations women, including but not limited to increased stress, increased healthcare visits and monitoring, exhaustion, inconvenience, fear, emotional strain, and shame. Positive lifestyle changes were also apparent for many of the women, such as improved eating habits, increased physical activity, increased knowledge of diabetes, and an opportunity to be a positive role model for other family members. Living with diabetes in pregnancy was characterized by a struggle for control, and at the same time a striving to control blood sugar levels. For some of the women diabetes in pregnancy produced a chance to take control of their health. The extent to which the women felt they could control their diabetes and their health played a crucial role in determining how challenging or positive their pregnancy experience was. Both the women's support systems (including family, healthcare provider, cultural/community, and internal support) and tangible resources to manage their diabetes (particularly awareness and preceding knowledge of diabetes) strongly influenced the capacity to control their diabetes and their health.

5.2 Data Integration and Implications for Practice

Triangulation is typically utilized in mixed methods research for data integration where qualitative and quantitative methods were used to examine different aspects of an overall research question or research project (1). It has been suggested that mixed methods data triangulation can be used to compare, contrast, validate or corroborate qualitative and quantitative findings. However definitions vary and practical examples in the literature are scarce, particularly for multiphase mixed methods designs (2). In fact, Wolf (3) proposed that triangulation strategies need to be 'tailor-made' to fit the research project. Accordingly, the qualitative and quantitative findings in this thesis were integrated through a simple convergence triangulation protocol that was adapted from that described by Creswell and Plano Clark (2). Data were collected and analyzed independently for each component and two sets of findings were produced. To help determine the practical implications and how healthcare providers can help improve pregnancy health for First Nations women, the salient findings from each phase were 'merged' and a consideration of where and how the main findings likely interact with each other in the real world was carried out.

A conceptual model of the integrated qualitative and quantitative findings can be seen in Figure 5.1. Having a strong support system, as well as awareness and resources to manage diabetes in pregnancy, increases the women's feelings of control over their own health. The predictors of diabetes in pregnancy and other epidemiological information identified from the quantitative phase can be used to enhance both healthcare provider support and the women's awareness and knowledge of diabetes in pregnancy. As women with diabetes in pregnancy gain

Figure 5.1 Model of the integrated qualitative and quantitative findings. “+” denotes increase and “-“ denotes decrease.



autonomy regarding their health, they are likely to experience less challenges and more positive lifestyle changes. Moreover, increased control over their health will also likely result in less pregnancy risk and adverse infant outcomes and less diabetes in pregnancy overall. Within the conceptual model there are several key areas where improvements to the healthcare system may effectively lead to healthier pregnancies and less diabetes in pregnancy among First Nations women.

First Nations women with diabetes in pregnancy would likely benefit from a more patient-centered approach to care that increases their feelings of support and autonomy (4). Such an approach should allow for mutual exchanging of information, shared power and decision making, and an even patient-provider partnership where providers actively listen to patients and learn in-depth about their life circumstances. As a result, provider care is less demanding, paternalistic and fear-inducing, and more positive, encouraging, and validating. Also, since emotional distress, anxiety, and stress were common among the women in the qualitative study and antenatal risks were higher among First Nations women in general, access to psychological services should be part of diabetes in pregnancy healthcare.

Healthcare providers should work to strengthen women's support systems beyond solely that of healthcare provider support. Spouses and other family members should be engaged and involved as much as possible during clinic visits throughout the pregnancy (and ideally preconception). Other cultural and/or community supports should also be included if possible and if required, such as Elders or close friends. Peer support or cultural support programs are needed,

particularly for those that lack family support. Women's internal drive to protect their fetus should also be stoked by providers through positive encouragement rather than fear inducement.

Providers should be mindful of the potential lack of awareness of diabetes in pregnancy and subsequent overwhelming nature of the information they provide. Strategies are needed to enhance the awareness and knowledge of diabetes in pregnancy, including early predictors of diabetes in pregnancy. Such strategies could include social marketing campaigns targeting diabetes in pregnancy and addressed to communities. A similar approach has been used previously in a Cree community in northern Ontario where multiple local communication strategies were associated with an increased awareness of iron deficiency anemia in infants as well as increased self-reported use and sales of iron-rich infant food (5). Social media could also be used to improve awareness (as was suggested in the qualitative participant group meeting), such as community podcasts or interactive online support groups. These or other primary prevention strategies should also target preconception in order to prevent GDM, plan pregnancies complicated by pregestational type 2 diabetes, and ultimately reduce the prevalence of diabetes in pregnancy.

5.3 Significance of Findings

Accurate estimates of both GDM and pregestational diabetes in First Nations women in Alberta have been provided, allowing government and healthcare organizations to translate knowledge into policy and funding decisions,

to plan healthcare delivery, and to evaluate efforts and assess their cost-effectiveness. As type 2 diabetes remains a public health crisis for First Nations peoples (contributed to in-part by high rates of diabetes in pregnancy), providing the best possible care for First Nations women with diabetes in pregnancy should therefore be a healthcare priority. This project offers healthcare professionals knowledge of the experiences First Nations women with diabetes in pregnancy may encounter, and it is hoped this will enable more supportive, respectful and effective pregnancy care. The findings may be translatable to other Aboriginal groups within Canada and in other countries with similar Indigenous health issues (such as Australia, New Zealand, and the United States), and to non-Aboriginal women as well.

This thesis is innovative because it deals with and helps close a knowledge gap of an essential aspect of the diabetes epidemic not fully understood until recently, and should lead to enhanced care for First Nations women affected by diabetes in pregnancy. Continuing with the subsequent phases of the planned overall mixed methods project, and based on results of this thesis, a community-derived pilot intervention for improving awareness and outcomes among women with diabetes in pregnancy will be planned.

5.4 Future Research

Future and ongoing monitoring of rates of diabetes in pregnancy and pregnancy outcomes will be needed. Such observations should include healthcare utilization rates as well. Epidemiological data on diabetes in pregnancy among

other Aboriginal populations (Métis, Inuit, non-registered Aboriginal women) are required. Age-adjusted prevalence data is needed in other provinces for more informative comparisons across ethnic groups and future studies are needed to identify the reasons for regional variations. More complex and inclusive studies are called for to assess the contribution of other potential contextual predictors to the logistic regression models such as healthcare access, lifestyle, social environment, income, etc. Studies are required to assess the impact and effectiveness of patient-centered care approaches to diabetes in pregnancy care. Such studies should include primary data collection and comparison such as monitoring of blood glucose and hemoglobin A1c throughout pregnancy, care satisfaction scales, provider satisfaction surveys, etc.

The narrow research questions of the qualitative study did not allow for in-depth inquiry into the preconception or postpartum experiences, and qualitative studies are needed to help uncover ways to prevent both diabetes in pregnancy and subsequent postpartum type 2 diabetes. Future qualitative work is also needed to understand the perspectives of those that have strong influences on pregnant First Nations women, such as healthcare providers, spouses and/or other family members, as well as others within Aboriginal communities (such as Elders). Moreover, the experience of diabetes in pregnancy should also be explored in other Aboriginal populations, including Métis women, Inuit women, and the more underprivileged Aboriginal women that receive little prenatal care and 'fall through the cracks'.

Community-based participatory research projects are required to address the lack of awareness and knowledge of diabetes in pregnancy, to improve care, and to prevent GDM and reduce the prevalence of diabetes in pregnancy. Creative interventions that are designed in collaboration with communities are needed and their effectiveness will need to be assessed.

5.5 References

1. O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. BMJ. 2010;341:c4587.

2. Creswell J, Plano Clark VL. *Designing and Conducting Mixed Methods Research 2nd Edition*. Thousand Oaks, CA: SAGE Publications; 2011.

3. Wolf F. Enlightened eclecticism or hazardous hotchpotch? Mixed methods and triangulation strategies in comparative public policy research. J Mix Methods Res. 2010;4(2):144-67.

4. Dwamena F, Holmes-Rovner M, Gaulden CM, Jorgenson S, Sadigh G, Sikorskii A, et al. Interventions for providers to promote a patient-centered approach in clinical consultations. Cochrane Database Syst Rev. 2012;12:12:CD003267.

5. Verrall T, Napash L, Leclerc L, Mercure S, Gray-Donald K. Community-based communication strategies to promote infant iron nutrition in northern Canada. Int J Circumpolar Health. 2006;65(1):65-78.

APPENDICES

Appendix 1 Government of Alberta Delivery Records

Government of Alberta ■

Delivery Record - Part One

Antenatal Risk Assessment

Part A - Pre-Pregnancy (circle if applicable)

Score	
1	Age ≤ 17 at delivery
2	Age ≥ 35 at delivery
1	Weight ≥ 91 kg
1	Weight ≤ 45 kg
1	Height < 152 cm
	Diabetes
1	Controlled by diet only
3	Insulin used
3	Retinopathy documented
	Heart Disease
1	Asymptomatic (no affect on daily living)
3	Symptomatic (affects daily living)
	Hypertension
2	140/90 or greater
3	Antihypertensive Drugs
2	**Chronic Renal Disease Documented**
1	**OTHER medical disorders** e.g. epilepsy, severe asthma, lupus, Crohn's disease

Part B - Past Obstetrical History (circle if applicable)

Score	
3	Neonatal death(s)
3	Stillbirth(s)
1	Abortion between 12 to < 20 weeks and birth weight <500 grams
1	Delivery at 20 - 37 weeks
2	Cesarean section
1	Small for dates - 5th percentile
1	Large for dates - 95th percentile
1	RH Isoimmunization - unaffected infant
3	RH Isoimmunization - affected infant
1	Major cong. anomaly e.g. Chromosomal, Heart, CNS defects

Part C - Problems in Current Pregnancy (circle if applicable)

Score	
2	Diagnosis of large for dates
3	Diagnosis of small for dates
2	Polyhydramnios or oligohydramnios
3	Multiple pregnancy
3	Malpresentation (breech or transverse lie)
2	Membranes ruptured before 37 weeks
1	Bleeding < 20 weeks
3	Bleeding ≥ 20 weeks
2	Gestational hypertension
1	Proteinuria ≥ 1+
1	Gestational diabetes documented
3	Blood antibodies (Rh, Anti C, Anti K, etc.)
1	Anaemia (Hgb< 100 gm. per L)
1	Pregnancy > 41 weeks
1	Poor weight gain (26 - 36 weeks<0.5kg/week or weight loss)
1	Smoker - anytime during pregnancy

Part D - Other Risk Factors (circle if applicable)

Score	
3	Major fetal anomaly
3	Acute Medical Disorder (acute Asthma, Thyrotoxicosis, UTI, etc.)
3	Cervical surgery
	Substance use:
3	Alcohol - ≥ 3 drinks on any one occasion during pregnancy
3	Alcohol - ≥ 1 drink per day throughout pregnancy
3	Drug dependent

Total Antepartum Risk Score

Intrapartum Risk Assessment

Score	(circle if applicable)
2	≤ 34 weeks
1	35 - 36 weeks
1	Meconium in labour
1	Gestational hypertension
1	Anemia
1	Fever
1	Fetal heart rate abnormalities
1	Bleeding
1	Ruptured membranes > 24 hrs.
1	Seizures
1	Coagulopathy

Total Intrapartum Risk Score

Indications for Induction

(circle primary indication)

1. Significant antepartum hemorrhage
2. Evidence of fetal compromise
3. Current intrauterine death
4. Term, prelabour rupture of membranes
5. Evidence of Intrauterine growth restriction
6. Gestational hypertension
7. Past history perinatal death
8. Diabetes
9. Gestational diabetes
10. Gestation > 41 weeks
11. Evidence of large for gestational age
12. Chronic essential hypertension
13. Social
14. Other, Specify _____

Operative Delivery (c/s/, forceps, vacuum extraction)

(circle primary indication)

1. Elective repeat c/s
2. Malpresentation (breech or transverse lie)
3. Arrest of progress in labor - first stage
4. Arrest of progress in labor - second stage
5. Failed trial of forceps
6. Fetal heart rate abnormalities
7. Intrapartum hemorrhage
8. Pyrexia in labor
9. Maternal hypertension
10. Maternal cardiac disease
11. Maternal endocrine disease (diabetes)
12. RH isoimmunization
13. Fetal malformation
14. Fetal illness (low platelets, etc.)
15. Multiple pregnancy
16. Prior hysterotomy
17. Placenta previa
18. Advanced maternal age
19. Maternal exhaustion
20. Maternal request
21. Other, specify _____

Date Signature

Guidelines Delivery Record

The delivery record revisions have been made to improve the record as both a clinical and data collection tool. Documentation on the record is a collaborative responsibility of the physician, midwife and nurse caring for the patient during labor and at delivery. The physician/midwife caring for the patient at the time of delivery is responsible to ensure accuracy of the documentation prior to signing the record. Comments on the revisions and/or recommendations for improvement can be directed to the Alberta Perinatal Health Program, Suite 101 Kingsway Professional Centre, 10611 Kingsway Avenue, Edmonton AB T5G 3C8.

Part One

Antenatal Risk Assessment

Total the scores of part A, B, C, and D.
Low Risk 0 - 2, Moderate Risk 3 - 6 , High Risk ≥ 7

The risk scores are cumulative and not exclusive of each other. For example, Part A - Pre-Pregnancy, if the patient is diabetic with retinopathy, the patient would score a total of 7 , ie: patient would score 1 point if she has diabetes, 3 points if she is on insulin, and an additional 3 points for the presence of retinopathy.

DEFINITIONS

Live Birth: The complete expulsion or extraction from the mother, irrespective of the duration of pregnancy, of a fetus in which, after expulsion or extraction there is breathing, beating of the heart, pulsation of the umbilical cord or unmistakable movement of voluntary muscle, whether or not the umbilical cord has been cut or the placenta attached. *Note: in Alberta all live births must be registered with the Vital Statistics Department, regardless of birth weight or gestation.*

Stillbirth: The complete expulsion or the extraction from the mother after at least 20 weeks' pregnancy, or after attaining a weight of 500 grams or more, a fetus in which, after expulsion or extraction there is no breathing, beating of the heart, pulsation of the umbilical cord or unmistakable movement of voluntary muscle.

Gravida: Total number of pregnancies for this mother, including this pregnancy.

Term: Total number of babies born to this mother at ≥ 37 weeks gestation, excluding this birth. *Note: if mother was a gravida 1 and had twins at 38 weeks, she would be G1T2 .*

Preterm: Total number of babies born between 20 and 37 completed weeks of gestation.

Abortions: Total number of pregnancy losses prior to 20 weeks gestation and less than 500 grams birth weight , including ectopic pregnancies.

Living: Total number of children currently living born to this mother, *excluding this birth.*

Neonatal Death: Death of an infant born alive to this mother that occurred within 28 days of age.

Small for Gestational Age: Infant's birth weight below the 5th percentile for gestational age.

Large for Gestational Age: Infant's birth weight above the 95th percentile for gestational age.

Major Congenital Anomaly: Includes any lethal anomaly, any anomaly that requires corrective surgery or any other anomaly that has a major effect on growth and development or quality of life.

Acute Medical Disorder: Refers to the presence of a significant medical condition that may affect the pregnancy or which may adversely be affected by the pregnancy. This may include a new medical disorder which appears during the pregnancy or it may be an acute attack or exacerbation of a pre-existing medical disorder.

Drug Dependent: Implies inappropriate or excessive use of any substance which may adversely affect the outcome of the pregnancy or the newborn.

Intrapartum Risk Assessment

The intrapartum risk assessment components are to be scored when the mother is admitted in labor and/or for induction of labor. These factors are known to be associated with potential risk to the fetus or the mother. *As these factors have not been validated an arbitrary risk score has been assigned.*

Government of Alberta

Delivery Record - Part Two

Intended hospital/ place of birth | Hospital/ place of birth

Referring Physician/Midwife | Maternal age | Maternal blood group

Gravida | Term | Preterm | S. Abort | Ind. Abort | Ectopic | Living | No.of Prior C/S's

Pregnancy Type ☐ Single ☐ Multiple ☐ A ☐ B ☐ C ☐ Other:

EDB Year / Mo. / Day | Gestational Age (Completed Weeks) | Total ARS | Total IRS

Assisted Conception ☐ Nil ☐ Ovulation induction ☐ IVF ☐ Intracytoplasmic sperm injection ☐ Other

Type Of Labour ☐ Spontaneous ☐ Induced ☐ Trial of labour after previous C/S

Cervical dilation on admission: cm.

Induction ☐ Prostaglandin - Cervical ☐ Prostaglandin - Vaginal ☐ Oxytocin ☐ Foley cath ☐ ARM ☐ Other, *specify*

Augmentation ☐ ARM ☐ Oxytocin

Pain Management In Labour	Medication	Dose	Time
☐ Nil ☐ Narcotic →			
☐ Inhalation ☐ Epidural time started:			
☐ Other, *specify*			

Anaesthesia ☐ Nil ☐ Local ☐ Pudendal ☐ Other, *specify* ☐ Epidural ☐ Spinal ☐ General

Medications ☐ Nil ☐ Antihypertensives ☐ Anticonvulsants ☐ Tocolytics

☐ Antibiotics ☐ <2 doses ☐ ≥2 doses First dose (Date/time)

☐ Other, *specify* ▸

☐ Steroids ▸ First Dose (Date / Time) ▸ ▸ #Doses

Presentation In Labour ☐ Cephalic ☐ Cephalic after version ☐ Breech ☐ Other, *specify*

Vaginal Birth (✓ all that apply)

Station: ☐ 0 ☐ +1 ☐ +2 ☐ +3 ☐ +4 (Outlet)

☐ Spontaneous ☐ Vacuum ☐ Forceps ☐ Forceps w/rotation

☐ Assisted breech ☐ Extracted breech ☐ Forceps to after coming head

Indication for assisted vaginal birth

Cesarean Birth (✓ all that apply)

☐ Primary ☐ Repeat ☐ Elective ☐ Low segment ☐ Classical ☐ T incision

Dilation at last exam: cm.

Indication for cesarean birth:

Episiotomy ☐ Nil ☐ Mediolateral ☐ Midline

Laceration ☐ Nil ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ Cervical ☐ Labial ☐ Periurethral ☐ Vaginal sidewall

Sutures:

Third Stage

Oxytocic: | Dose: | Route: | Time:

Placental / Cord Abnormality ☐ No ☐ Yes (Describe) ☐ To Pathology

Cord Vessels ☐ 3 ☐ 2

Placenta Delivery ☐ Spontaneous ☐ Manual

Blood Loss: ☐ Average (< 500 vag OR < 1000 c/s) ☐ Excessive (≥ 500 vag OR ≥ 1000 c/s)

Blood Transfusion ☐ No ☐ Yes

Obstetrical Comments

Antepartum Physician/Midwife | Intrapartum Physician/Midwife

Delivery Physician/Midwife | Consultant

Signature of Delivery Physician/Midwife | Nurse/other staff at delivery (name/title)

Mother's Postal Code

Description	Time Hrs / Min	Date Yr / Mo / Day	Duration of Labour
Adm. to hospital/birth centre			Hrs / Min Stage
Adm. to labour and delivery			
Start of labour			1
Fully dilated			2
Start of pushing			3
Birth			Total
Placenta			
Rupture of membranes			☐ SRM ☐ ARM

Fetal Surveillance (✓ all that apply) ☐ Nil ☐ Auscultation ☐ Electronic - External ☐ Electronic - Internal ☐ Normal ☐ Atypical ☐ Abnormal

Comments:

	Base Excess	Arterial Value	Venous Value
☐ Scalp pH			
☐ Cord pH			

Meconium Fluid ☐ None ☐ Thin ☐ Thick

Resuscitative Measures (✓ all that apply) ☐ No intervention ☐ Suction ☐ Bag & mask - room air ☐ O_2 Free flow ____% ☐ Bag / Mask O_2 ____% ☐ ET Tube-MEC ☐ ET Tube-PPV ☐ Chest compressions ☐ Medication *(specify)*

APGAR Score	0	1	2	1 Min	5 Min	10 Min
Heart rate	Absent	Under 100	Over 100			
Respirations	Absent	Slow irreg.	Good crying			
Muscle tone	Limp	Some flexion	Active			
Reflex	None	Grimace	Cough/Sneeze			
Colour	Blue or Pale	Body pink Limbs blue	Pink			
			Total ▶			

Stillbirth ☐ Antepartum ☐ Intrapartum

Signature: name/title

Medication For Baby Eye Care ☐ Yes ☐ No Vitamin K ☐ IM ☐ PO ☐ No

Birth Weight gms. **Sex:** ☐ Male ☐ Female ☐ Not Known

Pediatric Comments:

Anomaly	☐ Yes	☐ No	
Neonate voided	☐ Yes	☐ No	
Neonate passed meconium	☐ Yes	☐ No	
Breast feeding	☐ Yes	☐ No	
Breast fed after delivery	☐ Yes	☐ No	
NICU admission	☐ Yes	☐ No	
Maternal GBS status	☐ Neg	☐ Pos	☐ Not Known
Maternal hepatitis B status	☐ Neg	☐ Pos	☐ Not Known
Maternal HIV status	☐ Neg	☐ Pos	☐ Not Known
Maternal syphilis status	☐ Neg	☐ Pos	☐ Not Known

Baby attendant(s) at delivery (name(s) / title)

Baby Physician | Baby chart number | Baby Personal Health Number

HS0001-126-2 (2009/10)

Guidelines Delivery Record - Part Two

Admission to Hospital/Birth Centre: Document time (24hr clock) and date patient was admitted to hospital/birth centre regardless of the reason for admission.

Admission to Labour & Delivery: Document time (24hr clock) and date the patient was admitted for labour and birth. This will include admissions in spontaneous labour or for induction of labour.

Start of Active Labour: Indicate time, year, month, day that active labour was confirmed (dilatation greater than 3 cms and start of regular contractions). If the start of active labour is uncertain, document the time the woman experienced regular contractions.

Intended Hospital/Place of birth: Indicate the *planned hospital/place of birth* if it differs from the *hospital or place of birth. Note: place refers to home, alternative birthing centre or other province/country.*

EDB: Indicate the most reliable expected date of birth as determined by dates or ultrasound.

Gestational Age: Calculate the gestational age of the fetus in completed weeks based on the EDB.

Total ARS: Enter the total Antepartum Risk Score from *Delivery Record Part One.*

Total IRS: Enter the total Intrapartum Risk Score from *Delivery Record Part One.*

Type of labour: cervical dilation on admission: Document the cervical dilation in centimetres on admission if the patient is in spontaneous labour or if she is admitted for an induction.

Induction: Check the method(s) of induction used to effect labour in this patient. Note: Prostaglandin for cervical ripening is considered as an induction as the intent is to effect labour. Note that Cervidil would be documented as prostaglandin - vaginal. Include induction of labour if initiated as an outpatient. *Note: Circle the primary indication for induction on Delivery Record Part One.*

Augmentation: Check the method(s) used to improve the quality of uterine contractions in the labouring patient.

Fetal Heart Surveillance: Check all methods of fetal heart surveillance that apply. Indicate if **Fetal Monitoring** is normal, atypical or abnormal.

Comments: *Describe any fetal heart rate abnormalities.*

Pain management and/or anaesthesia: If epidural is *used both for analgesia and for cesarean birth, it should be checked in both places. If spinal or combined spinal and epidural is used please specify under other.*

Medications: Check all that apply. Steriods - indicate the date and time of first dose and total number of doses, including doses given prior to hospital admission. Antibiotics - indicate the date and time of first dose in space provided.

Obstetrical Comments: Document any relevant information relating to this birth, including the use of forceps or vacuum to facilitate descent, uterine rupture, third stage, abnormalities of placenta or cord, or fetal concerns.

Second stage of labour: Indicate the date and time of full cervical dilation (10 centimeters).

Resuscitative Measures: Check all that apply. A detailed description of resuscitation provided should be documented in the comments or progress notes.

APGAR SCORE: Score each category at 1 and 5 minutes and total. An infant with an APGAR score of less than 7 at 5 minutes should have a documented 10 minute APGAR. The APGAR score is to be assigned by the health care professional attending the baby after birth, ie. nurse, physician, midwife.

Stillbirth: If the baby is determined to have died in utero, check if the death was antepartum or intrapartum.

Signature: The person assigning the APGAR score is to sign name and title. Note: changes to the APGAR score are to be initialed and documentation as to the rational for changes given in the pediatric comments.

Pediatric Comments: Check all that apply. Comments could include description of resuscitative measures, fetal anomalies, baby's response to breast feeding, skin to skin contact etc. as is appropriate.

Baby Chart Number: The infant's chart identification number. Obtain **Baby Personal Health Number** if Live Birth.

Appendix 2 Recruitment Poster

Department of Medicine, University of Alberta

VOLUNTEERS NEEDED FOR RESEARCH INTERVIEWS

FIRST NATIONS WOMEN

AND

DIABETES IN PREGNANCY

We are looking for volunteers to interview about their experience of diabetes in pregnancy. The interview takes about 30-60 minutes. In appreciation for your time, you will receive $50.

We are looking for women who:

- Are of First Nations heritage;
- Are age 18 years or older;
- Had diabetes while pregnant within the last 5 years:
  - *Your diabetes could have been diagnosed before your pregnancy, or during your pregnancy;*
  - *Even if your diabetes went away after you were pregnant, you are still eligible for this study;*
- Received diabetes and pregnancy care in Edmonton.

If you are interested, please call **780-492-3859** or email **roster@ualberta.ca**

This study has been reviewed and approved by the Health Research Ethics Board - Health Panel at the University of Alberta.

Diabetes in Pregnancy Interview
780-492-3859 / roster@ualberta.ca

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Appendix 3 Information and Informed Consent Sheets

University of Alberta

INFORMATION SHEET

Title of Research Project: Diabetes in pregnancy among First Nations women in Alberta: a multiphase mixed-methods approach

Co-Investigator:
Richard Oster, MSc
University of Alberta
Phone: 780-492-3859
Email: roster@ualberta.ca

Principal Investigator:
Ellen Toth, MD
University of Alberta
Phone: 780-407-3636
Email: ellen.toth@ualberta.ca

Purpose
If you have diabetes when you are pregnant, this increases your chances of getting diabetes when you are older. It also increases your baby's risk for getting diabetes later in life. That's why getting good health care is so important when you are pregnant.

But what type of pregnancy care will help Aboriginal women? We want to learn what it is like for Aboriginal women who get diabetes when they are pregnant, and how to help them and their babies.

Methods
If you agree to be in this study, you will be interviewed by a researcher. An interviewer will have a few questions to help start the conversation, and we would like you to talk about what it is like to have diabetes while pregnant. The interview will last about 30-60 minutes, and will be recorded.

Voluntary Participation
You do not have to be in our study.

If you do agree to be in our study, you can change your mind up until six weeks after the interview day.

You can refuse to answer any questions in the interview. You can stop an interview at any time. If you don't want us to use your interview in our research,

you will have six weeks after the interview day to ask us to take out your information.

Analysis
Audio recordings of your interview will be typed up into a written transcript. Personal information that could identify you will be removed (for example, your name, date of birth). Transcripts and audio recordings will be kept for ten years, and then will be destroyed by the researchers.

Confidentiality
The information from your interview will be used for a research project. Only the researchers will be able to see your interview transcripts. Your name will not be used. Your interview transcripts will be kept on a password protected computer.

Benefits
This study may or may not have any direct benefits for you. You may learn about diabetes and having a healthy pregnancy. You may feel better after talking about your experience of having diabetes when pregnant.

Risks
We do not expect this study will harm you. However, if you would like to speak to someone after an interview, please contact the "**co-investigator"** or the **"principal investigator"** listed at the top of page 1.

Withdrawal from the study
If you agree to be in this study, you can change your mind at any time.

You can refuse to answer any questions in the interview. You can stop an interview at any time. If you do not want us to use your interview in our research, you will have six weeks after the interview day to ask us to take out your information. We will then destroy the audio recordings and transcripts immediately.

Use of your Information
Your interview will be recorded, typed up into a written transcript, and then analyzed. The results of this study may be published in medical journals or presented at health conferences. Your name will never be used.

Rights
Should you have any further questions about your rights as a research subject, feel free to contact the Research Ethics Office at 780-492-2615.

Thank you very much for taking part in this study.

CONSENT FORM

Title of Research Project Diabetes in pregnancy among First Nations women in Alberta: a multiphase mixed-methods approach

Co-Investigator:
Richard Oster, MSc
University of Alberta
Phone: 780-492-3859
Email: roster@ualberta.ca

Principal Investigator:
Ellen Toth, MD
University of Alberta
Phone: 780-407-3636
Email: ellen.toth@ualberta.ca

Please circle your answers:

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received the Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you can quit taking part at any point during the interview?	Yes	No
Do you understand that you can withdraw at any time during the data collection part of the study and that any comments that you provided up to that point will not be used?	Yes	No
Has confidentiality been explained to you?	Yes	No
Do you understand who will have access to the data collected?	Yes	No
Do you know that the information that you provide will be used for research purposes and then destroyed after ten years?	Yes	No
Do you understand that the interview will be audio-recorded and transcribed?	Yes	No
Do you understand that you have up until six weeks after the day of your interview to withdraw what you have shared in the interview?	Yes	No

If you have further questions regarding the research, please contact the principal investigator listed above.

This study was explained to me by: _____

I agree to take part in this study.

_____ _____
Signature of Research Participant Date (dd/mm/yyyy)

_____
Printed name