

Misconceived Expectations: Aboriginal Women's Experiences with  
Gestational Diabetes Mellitus in the Urban Context of Winnipeg, Manitoba

by

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This dissertation is dedicated to  
My Family,  
for all of their love, support and encouragement  
every step of the way.

## **Abstract**

More North American Aboriginal women are being diagnosed with gestational diabetes mellitus (GDM) than the general population. Despite the association of a number of health problems with GDM, there have been few evaluations of GDM prevention projects. Nor have investigators looked at Aboriginal women's understandings of GDM in an effort to develop appropriate and effective health strategies. A qualitative investigation was therefore proposed to describe the experiences of Aboriginal women with GDM. The study began with unstructured interviews and focus groups with 25 advisors such as maternal care providers and community representatives working with Aboriginal women. Semi-structured explanatory model interviews were then conducted with 29 Aboriginal women in Winnipeg, the capital city of Manitoba, Canada. Fixed-response interviews were also administered and analyzed using cultural consensus analysis to determine whether or not shared cultural understandings existed among the Aboriginal women participants. Results of the consensus analysis revealed biomedical understandings were the most commonly shared. A more variable response was associated with women's personal interpretations of GDM, leading to weak consensus overall. Thematic analysis of the semi-structured interviews illustrated the fear, anxiety and frustration many participants experienced with GDM. Women discussed their emotional reactions alongside negative relationships with food and other prescribed lifestyle treatments. These perspectives, combined with results from the group of advisors, pointed to communication and cultural barriers which may limit the quality of prenatal care received. Collectively the results suggest living with GDM can be overwhelming and underscore the need for health care providers to encourage self-

efficacy and emotional security towards effective management practices. Research contributing to a more comprehensive understanding of Aboriginal women's experiences with GDM is also required, to provide further perspective for diabetes prevention and positive change.

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## Chapter One

### Introduction and Study Objectives

#### Background

Rates of type 2 diabetes mellitus are reaching epidemic proportions among North American Aboriginal<sup>1</sup> populations (Young et al., 2000; Yu and Zinman, 2007). Rates of gestational diabetes mellitus (GDM) are also higher among Aboriginal women than the general population in Canada, New Zealand and Australia (Aljohani et al., 2008a; Dyck et al., 2010; Godwin et al., 1999; Harris et al., 1997; Ishak and Petocz, 2003; Moum et al., 2003; Rith-Najarian et al., 1996; Rodrigues et al., 1999a; Simmons et al., 1999). Women who have had GDM are more likely to develop type 2 diabetes. Their children tend to be heavier with higher blood sugar levels and have the increased potential to become diabetic as they get older. Aboriginal women with GDM may also experience increased rates of hypertension, pre-eclampsia and other complications during pregnancy and delivery that may lead to poor maternal, fetal and infant health outcomes (Aljohani et al., 2008b; Dyck et al., 2002; Gray-Donald et al., 2000). Previous research on Aboriginal women with GDM has mainly examined and compared prevalence rates and risk factors (Aljohani et al., 2008a; Harris et al., 1997; Rodrigues et al., 1999a). Few investigators have looked at Aboriginal women's understandings of GDM, particularly in an urban context (Smith-Morris, 2006a and 2006b). A qualitative investigation was therefore proposed to describe the experiences of Aboriginal women with gestational diabetes accessing care in the city of Winnipeg, Manitoba.

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<sup>1</sup> In Canada, "Aboriginal" includes status and non-status First Nation, Inuit and Métis people (Frideres and Gadacz, 2001) and will be used throughout this document to refer to the women of self-declared First Nation and Métis backgrounds who participated in this study.

Gestational diabetes mellitus has been defined as glucose intolerance of variable severity with onset or first recognition during pregnancy (Metzger and Coustan, 1998; US Preventive Services Task Force, 2008). Glucose levels usually return to normal after the child's birth; however, if levels remain high post-partum, women are reclassified as having type 2 diabetes (CDA, 2008). Rates of GDM appear to reflect the rising incidence and prevalence of type 2 diabetes among Aboriginal populations in general (Ben-Haroush et al., 2003; Boinpally and Jovanovi , 2009; King, 1998). Several studies have investigated risk factors associated with the rising rates of GDM in Canadian Aboriginal populations (Aljohani et al., 2008b; Dyck et al., 2002; Godwin et al., 1999; Harris et al., 1997). The majority of this research has, however, concentrated on screening for and comparing GDM rates based on ethnicity between populations of Aboriginal and non-Aboriginal women. Reported prevalence rates for GDM range from 4.6% among Navajo women to 15.3% in Zuni, compared to between 0.15 - 14.5% in the general U.S. population (Benjamin et al., 1993; LaVallie et al., 2003; Massion et al., 1987; Moum et al., 2004; Sugarman, 1989). In Canada, studies have reported rates spanning 11.5 - 12.8% among Ojibwa-Cree and James Bay Cree compared to 3 - 5% in the overall population, (CDA, 2008; Gray-Donald et al., 2000; Harris et al., 1997; Rodrigues et al., 1999a) with a 6.9% prevalence found among First Nation women in Manitoba (Aljohani et al., 2008a). Another more recent Québec study revealed prevalence rates as high as 14.9% and 27.4%, respectively, among Cree women who were overweight or obese at the onset of pregnancy (Brennand et al., 2005). According to Health Canada (2003) the

classification of overweight is defined as a body mass index (BMI) of 25.0 kg/m<sup>2</sup> while obesity refers to a BMI of 30.0 kg/m<sup>2</sup> or higher.

The most commonly reported risk factors for GDM are increased maternal age, high weight, parity, the previous delivery of a macrosomatic infant, and a family history of type 2 diabetes (CDA, 2008). Macrosomatic infants frequently born to diabetic mothers can lead to higher rates of caesarean section, shoulder dystocia, asphyxia and other birth traumas (Dyck et al., 2002; Petticca et al., 2009; Rodrigues et al., 1999b; Weindling, 2009; Yogev and Visser, 2009). Aboriginal women with GDM are also more likely to experience preterm labour, hypertension, pre-eclampsia and other complications during pregnancy and delivery that may potentially lead to serious maternal, fetal and infant health outcomes, such as an increased lifetime risk of type 2 diabetes for mother and child (Aljohani et al., 2008; Cheung and Byth, 2003; Dyck et al., 2002; Gray-Donald et al., 2000; Pettitt and Knowler, 1998). Authors of a recent systematic review reported a seven-fold increased risk of developing type 2 diabetes for women who have had GDM compared to those who have had a normoglycemic pregnancy (Bellamy et al., 2009; Feig et al., 2008). The long-term risks to off-spring of women with GDM are also becoming well known. Research from the Pima population in Arizona indicated that 70% of children exposed to diabetes in utero had type 2 diabetes diagnosed between the ages of 25–35 years (Dabelea et al., 2000).

Controversy continues to exist, however, as to the extent to which GDM is associated with increased perinatal complications and poor maternal-fetal health outcomes. Advocates of strict, evidence-based medical care have argued there is

insufficient evidence that controlling maternal hyperglycemia will prevent morbidity (Tuffnell et al., 2003). A number of serious health risks have, however, been associated with GDM and even minimal hyperglycemia (Buchanan and Kjos, 1999; LaVallie et al., 2003). Recent data from the multi-centre Hyperglycemia and Adverse Pregnancy Outcomes (HAPO) study have demonstrated that even subclinical hyperglycemia was significantly associated with large-for-gestational-age births. There were also associations between neonatal hypoglycemia and primary caesarean delivery. Another recent study also found that a hyperglycemic intrauterine environment significantly increases the probability of adult offspring developing type 2 diabetes with either diet-treated GDM or type 1 diabetes during pregnancy (Clausen et al., 2008).

Now when it is becoming more evident that GDM is a growing health concern with potentially serious long-term consequences for both baby and mother, unfortunately guidelines to promote the universal screening and early detection of GDM are not firmly established. It has been proposed that these long-standing and vigorously debated circumstances may therefore lead to an under diagnosis and under management of GDM (Reece et al., 2009) even though recent studies have shown that not treating GDM is associated with poor pregnancy outcome (Crowther et al., 2005; Langer et al., 2005). There is still no consensus on screening method or establishing globally applicable threshold criteria (Yogev et al., 2009). Universal guidelines for preconception management and postpartum treatment of GDM for the early detection and prevention of type 2 diabetes also have yet to be proposed (Boinpally and Jovanovic, 2009; England et al., 2009; Kim, 2009; Metzger et al., 2007).

Studies have shown that intensive lifestyle intervention can delay or prevent the development of type 2 diabetes (Knowler et al., 2002; Ratner et al., 2008). There have also been some positive results from a pilot intervention study to prevent the development of GDM (Hui et al., 2006) with larger trials in the U.S and Europe currently on-going (Chasen-Taber, 2009 and Oostdam et al., 2009). Programs that focus on the prevention of gestational diabetes among Aboriginal women are remarkably few in the published literature, and unfortunately none have been particularly successful. A pilot project based in urban Saskatchewan, for example, attempted to discern if a supervised exercise program would positively influence glycemic control among Aboriginal women diagnosed with GDM (Dyck et al., 1998). Positive results were not confirmed perhaps due to the low participation rates. Gray-Donald and colleagues (2000) were involved in a community-centred intervention with four reserves in Québec. Their focus was on improving prenatal dietary intake, reducing excessive weight gain, and lowering glycemic levels and birth weight. Outcomes for the women were not positive, however, with 16.2% developing GDM in the intervention group compared to 14.7% in the control group. The Special Working Group of the Cree Regional Child and Family Services Committee (2000) responded to this study, recommending that pregnant women should be involved in group diabetes information sessions. Researchers and health professionals, they also suggested, need to develop a better understanding of local and historical factors of influence prior to starting any community-based initiative.

In an effort to develop appropriate health strategies, more information is needed about the wider set of social meanings attached to risk behaviours and the everyday

realities of people's lives (Thompson et al., 2000). The treatment and prevention of gestational diabetes require that approaches be culturally sensitive. To bring about understandings of GDM to change behavioural patterns requires insight into women's values and belief structures (Nicolaisen, 2008). Being diagnosed with GDM can provoke complex and diverse emotional reactions from women. Participants in Evans and O'Brien's (2005) qualitative study described GDM as an illness shadowed with an implication mother and child are both at risk. These perceptions of heightened uncertainty, they went on to suggest, may challenge women's autonomy and should consequently challenge health care professionals to reassess current models of prenatal care.

Although some informative studies on the topic of how Aboriginal men and women understand and interpret type 2 diabetes have been conducted (Barton et al., 2005; Bruyère, 1998; Garro, 1995; Garro, 1996; Gregory et al., 1999; Lang, 1985; Lang, 1989; Sunday and Eyles, 2001), very few qualitative studies have been published on GDM (Evans and O'Brien, 2005; Hjelm et al., 2005; Hjelm et al., 2006; Kieffer et al., 2002; Lawson and Rajaram, 1994). Smith-Morris is the only other author to my knowledge to conduct a qualitative study on Aboriginal women's conceptions of diabetes during pregnancy. She focussed on their views of risk and understandings of the diagnostic process. Her results with Pima women living on their reservation indicated that the way women respond to and think about GDM can provide insight into their health-seeking patterns and reactions to diabetes screening or prenatal care. For example, she found Pima women may delay prevention behaviours since they perceive GDM to be

a “work in progress” without definition or potentially dangerous health implications (Smith-Morris, 2005; p.164). Gestational diabetes was referred to as “symptomless” (Smith-Morris, 2006; p. 195) and as a result not necessarily a disease that can be prevented. Pima women questioned the long-term effectiveness of prevention behaviours because of the continuing high incidence and prevalence of type 2 diabetes in their communities (Smith-Morris, 2006). These findings are in contrast with a qualitative study on maternal dietary change (Neufeld, 2003). Two generations of Aboriginal women independently raised the topic of diabetes during pregnancy, based on their own experiences, and recommended preventive actions such as increased intakes of fresh foods and wild meat during pregnancy. The relevance of the topic to mothers and grandmothers in the study also suggested an awareness and receptivity towards the development of prenatal programs to prevent gestational diabetes (Neufeld and Marchessault, 2006).

### **Purpose of Study**

A qualitative investigation was proposed, to ask Aboriginal women about their illness experiences with gestational diabetes, and to determine the extent to which Aboriginal women from a variety of backgrounds currently accessing prenatal care or living in an urban context share understandings of GDM. The primary objective in conducting this study was to describe how Aboriginal women experience gestational diabetes based on their own explanations of the illness. More specific research goals included the exploration of how Aboriginal women understand the causes, course, treatment, onset, pathophysiology, and prevention of their condition, and to what extent

these cultural understandings are shared among a diverse population of Aboriginal women living in the city of Winnipeg.

Participants' understandings and experiences with GDM were explored using different interview formats. Three separate protocols were used to assist in developing a more comprehensive understanding of Aboriginal women's responses to and descriptions of their illness. The research began with unstructured interviews with research advisors<sup>2</sup>, including representatives from Aboriginal women's organizations and prenatal health clinics, to provide context for the interviews with Aboriginal women who had experienced a diabetic pregnancy. Next, Kleinman's Explanatory Model Framework (Kleinman et al., 1978) was utilized to conceptualize and understand Aboriginal women's experiences of GDM through open-ended questions framed around Kleinman's five themes: causation, onset, course of the illness, treatment, and pathophysiology with the added theme of prevention. Last, a more structured fixed-response interview based on statements from the participants was administered and analyzed using cultural consensus analysis to determine whether or not shared cultural understandings on the topic of gestational diabetes existed among Aboriginal women participants.

### **Organization of the Thesis**

This body of this work consists of three papers that were prepared in publishable format. The three manuscripts included are:

1. Urban Aboriginal women's understandings of gestational diabetes: An exploration using cultural consensus analysis. In the first paper, shared

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<sup>2</sup> Use of the term "advisor" is used throughout this document to replace the more common term of "key informant", which according to numerous authors can be viewed negatively (Smith, 1999; Oakley, 1981).



understandings on biomedical teachings associated with GDM were revealed through cultural consensus analysis. Many women, however had never met another woman with GDM, which may help to explain a lack of cultural consensus overall. It appears that GDM is not a frequent topic of conversation for this group of participants.

2. Food perceptions of Aboriginal women coping with gestational diabetes in Winnipeg, Manitoba. The second paper describes women's weight and food preoccupations in dealing with a pregnancy that is overshadowed by diabetes. In many cases, eating behaviours seemed to be emotionally mediated. Women talked about unstable eating patterns such as inconsistent meals, binging on foods of low nutritional quality and other dangerous practices such as self-induced vomiting to control blood glucose levels.

3. Patient's and caregivers' perspectives of health provision practices for Aboriginal women with gestational diabetes accessing services in Winnipeg, Manitoba. The third paper is an examination of Aboriginal women's experiences with the health care system in Winnipeg contrasted with the ideas and opinions of health care practitioners. The results illustrate how Aboriginal women's health care experiences are shaped by divisions of power and attitudinal barriers.

The dissertation also contains chapters on the theoretical as well as methodological frameworks used for the study, a review of the literature, a summary discussion, overall bibliography and appendices. Together, they help to form a picture of

what the experience of living with gestational diabetes in the urban setting of Winnipeg, Manitoba is like for Aboriginal women.

## **Chapter Two**

### **Literature Review**

This review of the literature will examine the evolution of gestational diabetes mellitus (GDM) as a clinical entity and place it in a context of current issues related to the epidemiology and risk assessment of women and infants. Current literature available on the topic of GDM treatment recommendations and the potential maternal and fetal outcomes will also be presented. The chapter will conclude with a summary of the mainly qualitative studies that exists on the experience of diabetes for Aboriginal populations. This final section will also include a short discussion of Aboriginal and non-Aboriginal women's perceptions and experiences GDM.

#### **Epidemiology and Assessment of GDM**

The clinical effects of gestational diabetes and its overall pathophysiology have spurred a wide diversity of opinion regarding its detection, diagnosis and management (Kjos and Buchanan, 1999). Hunter and Milner (1985) wrote that gestational diabetes is simply a diagnosis still looking for a disease. In 1979, the expert committee defined GDM at the first International Workshop Conference on GDM, as "any degree of glucose intolerance with onset or first recognition during pregnancy" (Metzger et al., 1980; 1998; p. B162). At the second International Workshop Conference in 1984, the definition of GDM was expanded to include: "the definition applies whether insulin or only diet modification is used for treatment and whether or not the condition persists after pregnancy. It does not exclude the possibility that unrecognized glucose intolerance may

have antedated or begun concomitantly with the pregnancy” (ADA, 1984; 2004; p. S88). According to Omori (2003), however, there are problems with the American Diabetes Association (ADA) definition and classification of GDM. Slightly impaired glucose tolerance (IGT) induced by pregnancy, as well as diabetes first diagnosed during pregnancy are all combined into one category (GDM) by the ADA. Omori suggests that if type 2 is first detected during pregnancy it should be referred to as type 2 diabetes diagnosed during pregnancy. A more appropriate definition, he suggests, was written by O’Sullivan and Mahan (1964), who developed the diagnostic criteria for GDM. They defined gestational diabetes as “a transient abnormality of glucose tolerance during pregnancy” (p. 278). Following the most recent Fifth International Workshop-Conference on GDM, Boinpally and Jovanovic (2009) proposed the current definition also be reconsidered to distinguish between newly occurring diabetes and long-standing diabetes.

**Prevalence and predictors of gestational diabetes.** The problems with the distinction of GDM, as it is currently defined from pre-existing but undiagnosed diabetes, has meant that its epidemiology has not been studied systematically (Ben-Haroush et al., 2003; King, 1998). Marked variation in its prevalence worldwide appear to have resulted from these differences in definition, diagnostic criteria, screening methods as well as corresponding incidence rates of diabetes mellitus in a given population (Metzger et al., 1998; Metzger et al., 2004). It remains difficult, therefore, to make direct comparisons among studies. As Stone and colleagues (2002) have stated, true incidence of GDM is unknown because of the lack of consistent universal testing, inconsistent diagnostic criteria and the absence of a uniform reporting system to a centralized register. Therefore

determining whether and to what extent there has been a global increase in prevalence of GDM is difficult. There is also variation in its prevalence associated with factors such as maternal age and ethnicity (Metzger et al., 2007).

There has however been general agreement in the scientific literature that GDM prevalence is on the increase (Dabelea et al., 2005; Getahun et al., 2008; Hunt and Schuller, 2007; Metzger et al., 2007; Stone et al., 2002; Vibeke et al., 2008). Gestational diabetes has been estimated to occur in approximately 3.7% of pregnancies in Canada, but rises to between 8 and 18% in Aboriginal populations (Aljohani et al., 2008a; CDA, 2008; Dyck et al., 2002; Godwin et al., 1999; Harris et al., 1997; Rodrigues et al., 1999a). A similar range of prevalence rates have been reported in the United States (1.0 to 14.0% of all pregnancies) depending on the population group and diagnostic test employed (ADA, 2009). The mean prevalence in the U.S. has been estimated to have grown from between 3 to 5% (Jovanovic and Pettitt, 2001) to 7% (ACOG, 2009; ADA, 2009). Other investigations, such as a recent study of 267 051 women from various ethnic backgrounds in Northern California, found that GDM incidence had increased by 35% from 1991 to 2000 (Ferrara, et al., 2004). Some have argued, however, that such an extreme variation and elevation in incidence rates, in particular, reflect the “unrealistic estimation caused by universal screening” (Di Cianni et al., 2003; p.132; MacNeill et al., 2001; Wen et al., 2000). MacNeill and colleagues (2001), who have also reported a significant increase in gestational diabetes rates in Nova Scotia, feel the rising incidence likely reflects increasing compliance with CDA guidelines for universal testing. Also given its definition, GDM encompasses undiagnosed type 2 diabetes prior to pregnancy and

changing screening and diagnostic practices ultimately influence prevalence rates (Hunt and Schuller, 2007). It has been suggested, for instance, that in the United States, of all pregnancies with diabetes, 40% are cases of as yet undiagnosed type 2 (Boinpally and Jovanovic, 2009).

**Risk factors for GDM.** The most commonly reported risk factors for gestational diabetes are increased maternal age, weight and parity, as well as the previous delivery of a macrosomatic infant and being a member of a “high risk” population, such as women of Aboriginal, Hispanic, South Asian, Asian and African descent (CDA, 2008). The most commonly identified risk factors for GDM are those of maternal origin and tend to conform to those risk factors traditionally associated with type 2 diabetes (King, 1998). For instance, a Canadian retrospective study by Xiong and colleagues (2001) identified age greater than 35 years, high BMI and an obstetric history of prior neonatal death or cesarean section as factors most commonly predictive of women developing GDM. Other maternal factors, such as low maternal birth weight, genetic predisposition or traits as well as specific dietary and environmental factors have been less formally explored in the literature (Metzger et al., 2007). Those unmodifiable risk factors, such as ethnicity, pre-pregnancy weight, age, parity and family history of diabetes are most often used to identify women most at risk. It has been suggested that strategies aimed at those women most at risk of GDM need to address risk factors that may potentially be modified, such as obesity, future weight gain, diet and other lifestyle factors that can influence insulin resistance and the pathophysiology of GDM (ACOG, 2009; Dornhorst and Rossi, 1998; England et al., 2009).

***Obesity and weight gain.*** Normal pregnancy has been characterized as a diabetogenic state of increased insulin resistance, primarily in the late second and third trimesters. Increased placental secretion of anti-insulin hormones during the second half of pregnancy also results in elevated levels of circulating maternal substrates to meet the needs of the rapidly developing fetus. In order to maintain normal glycemic levels as a result of this metabolic shift, maternal secretion of insulin increases during pregnancy (Yogev et al., 2003). Women who are unable to adapt to these changes may develop GDM. For example, several authors have demonstrated that overweight pregnant women have higher fasting and post-prandial blood glucose and insulin levels compared with leaner women (Hollingsworth and Ney, 1992; McMahon et al., 1998; O'Sullivan, 1989; Pettitt et al., 1996). High pre-pregnancy weight has also been demonstrated to increase risk for GDM independently of age, parity or ethnicity (Berkowitz et al., 1992; Solomon et al., 1997). Most investigations into risk factors for GDM list obesity as generally being associated with GDM however, according to Rodrigues (1999a), total gestational weight gain is difficult to estimate as a predictor of GDM because those women diagnosed and treated for GDM typically are encouraged to modify their diets and restrict energy intake, particularly women with obesity prior to pregnancy.

***Diet.*** The fed state of a normal pregnancy is characterized by metabolic changes of prolonged hyperglycemia and hyperinsulinemia. As such, glucose intolerance during pregnancy is a result of the inability to produce sufficient amounts of insulin as pregnancy-related insulin resistance continues (Catalano and Buchanan, 2004). There is evidence, that in addition to the increased metabolic stress of obesity during pregnancy,

diet is linked to the development of glucose intolerance. Diets that are either high in fat or foods with a high glycemic index have been recognized, for example, as risk factors in the development of type 2 diabetes (Anderson et al., 2006). Clinical trials have also demonstrated that dietary counseling and support may reduce the risk of type 2 diabetes (Knowler et al., 2002; Kosaka et al., 2005; Tuomilehto, et al., 2001) and reduce perinatal complications for women with GDM (Crowther et al., 2005). Few studies have investigated the relationship between diet and GDM from a causal perspective. Moses and colleagues (1997) also support these concepts, reporting women who developed GDM in a subsequent pregnancy consumed higher fat diets. Saldana and colleagues (2004), however, have demonstrated an association between increased fat intake and the development of glucose abnormalities during pregnancy.

***Physical activity.*** Exercise has been reported to have a beneficial effect on many aspects of insulin resistance, as well as increasing insulin sensitivity and decreasing subcutaneous fat deposits (Dornhorst and Rossi, 1998; Eriksson, et al., 1997). Decreases in physical activity have been linked with increases in the prevalence of type 2 diabetes (Lynch et al., 1996). The risk of developing type 2 diabetes has also been lowered by exercise in populations of both men and women, with the greatest benefits observed among those individuals most overweight (Manson, 1994). Randomized trials among women with GDM have reported the benefits of exercise in helping to maintain euglycemia (Jovanovic-Peterson et al., 1989; Rosas and Constantino, 1992). Population studies have reported inconsistent results (Dye et al., 1997; Solomon et al., 1997). Rodrigues (1999a) has also commented that the difficulties in accurately describing the



relationship between physical activity and GDM may be hampered by potential changes in physical activity patterns of women during pregnancy, which may not reflect their usual physical activity patterns, or by imprecise measures used to estimate physical activity (such as self-reported frequency questionnaires) in large population studies.

**Screening and diagnosis.** Screening for and making a diagnosis of gestational diabetes remain controversial and inter-related issues continue to be fiercely debated in the medical community internationally (Berger and Sermer, 2009; Moses and Cheung, 2009). Although there has been general agreement on the underlying concepts of the disorder since its initial framing, research and discussion have mainly focused on what constitutes the best method of screening for GDM. Of particular contention are: blood glucose level for diagnosis; number of tests and abnormal values necessary for diagnosis, and the overall need for screening procedures to detect unsuspected cases of hyperglycemia during pregnancy. Beginning as early as the 1950s, a number of protocols have been developed to test for and diagnose gestational diabetes. The standard protocol that is continued to be promoted by the American Diabetes Association (ADA, 2009) is the criteria endorsed by the U.S. National Diabetes Data Group (NDDG). This U.S., or NDDG criteria, as it is best known, is mainly used in North America. Internationally, the diagnostic standard is the World Health Organization (WHO) criteria.

The results of the Hyperglycemia and Adverse Pregnancy Outcomes (HAPO) study demonstrated that risk of adverse maternal, fetal and neonatal outcomes increased as a function of maternal glycemia. This multicentre international trial used the 75 gram load oral glucose tolerance test (OGTT) to discover that fasting plasma glucose was

sufficient to identify women at risk for adverse outcomes (HAPO, 2008). On the basis of this new information, it is assumed that an internationally recognized diagnostic test may be adopted (ADA, 2009). The most recent Canadian Diabetes Association (CDA) Clinical Practice Guidelines acknowledge the results of the HAPO study and have concluded that “the treatment of GDM is worthwhile” (2008; p.S171) even though the international approach to the diagnosis of GDM remains fragmented. Given the level of controversy surrounding diagnostic tests and appropriate cut-off values, the CDA has also recommended that other accepted methods may be used, even though a 75 gram OGTT is indicated in their guidelines (CDA, 2009). SOGC Clinical Practice Guidelines, however, do not recommend use of the WHO criteria. Its use, they contend, “will approximately double the number of women diagnosed with GDM without an apparent clinical benefit” (Berger et al., 2002).

***Strategies for screening.*** One of the main issues disputed in the scientific literature is who should be screened for GDM. This ongoing debate is compounded by further uncertainty surrounding the clinical significance of the disorder and any practical benefits of screening, even with the recent results from the HAPO study. As has been the case with diagnostic testing, the lack of agreement in screening for GDM is reflected in the different screening strategies proposed by various professional groups in the past. Identification of women at risk of developing GDM was initially based on the presence of a range of risk factors described in the previous section. Current guidelines continue to reflect this past practice, which is termed, ‘selective screening’. Selective screening for GDM is based on the presence of one or more risk factors and continues to be

recommended by the American College of Obstetricians and Gynecologists (ACOG), the Society of Obstetricians and Gynecologists of Canada (SOGC), and the ADA (ACOG, 2001; ADA, 2009; Berger et al., 2002).

Selective screening is, however, controversial. A number of authors have cautioned that such a screening strategy could miss a significant proportion of GDM cases (Coustan et al., 1989; Moses et al., 1998; Willams et al., 1999). The CDA is the only North American organization to recommend universal screening (2008) for all pregnant women between 24 and 28 weeks gestation. It is recommended those with multiple risk factors be screened during the first trimester instead. In Canada, the screening test recommended for GDM is a 1-hour plasma glucose (1hPG) measurement following a 50 gram glucose load given at any time of day. Gestational diabetes is confirmed if the 1hPG is greater than or equal to 10.3 millimoles per litre (mmol/L). If the 1hPG value is between 7.8 - 10.2 mmol/L a 75-g OGTT is recommended. If two or more values of fasting plasma glucose (FPG) values (greater or equal to 5.3 mmol/L, and 1hPG greater or equal to 10.6 mmol/L or 2hPG greater or equal to 8.9 mmol/L) are met or exceeded GDM is confirmed. If only one value is met or exceeded, impaired glucose tolerance (IGT) is diagnosed.

ADA guidelines (2009) recommend either a one or two step approach to screening. The one-step approach involves a diagnostic 100-g OGTT without prior plasma or serum glucose screening and is recommended for use among higher risk patients or populations. The two-step approach measures plasma or serum glucose concentration one hour after a 50-g glucose load. Those women exceeding a glucose

threshold value of greater than or equal to 140 mg/dl are then required to have a diagnostic 100-g OGTT.

### **Management and Treatment of GDM**

Once a diagnosis of GDM has been confirmed, close prenatal and early postpartum monitoring of the pregnancy is generally recommended. According to the most recent CDA guidelines, women with GDM are encouraged to regularly monitor preprandial and postprandial blood glucose to achieve glycemic targets and weight gain goals (CDA, 2008). Both the CDA and ADA guidelines encourage daily self-monitoring of blood glucose (SMBG) rather than intermittent laboratory monitoring. It is generally recommended that women with diet-controlled gestational diabetes test blood glucose levels four times per day (Jovanovic, 2004). Since starvation ketosis is common in pregnancy and may also have detrimental effects on the fetus, both CDA and ADA also recommend regular urine or blood monitoring of ketones, particularly in women treated with energy or carbohydrate restriction (ADA, 2007; CDA, 2008).

**Table 2.1: Recommended Glycemic Targets for Women with GDM**

	<b>Plasma Glucose (mmol/L)</b>
Fasting and preprandial	3.8 – 5.2 mmol/L
1-Hour Postprandial	5.5 - 7.7 mmol/L
2-Hour Postprandial	5.0 – 6.6 mmol/L

(Adapted from CDA, 2008)

**Dietary strategies.** A wide range of opinion currently exists with regard to various lifestyle and pharmacological interventions for women diagnosed with GDM.

Most experts do agree that nutrition therapy is the cornerstone of treatment. The diet prescribed for gestational diabetes has changed dramatically in recent decades and is currently similar to the diets recommended for non-diabetic women. Meeting the nutritional requirements of pregnancy while maintaining good metabolic control of diabetes, however, remains a challenge and unfortunately, specific dietary guidelines are inconsistent (Anderson, 2006). Current controversies mainly include the composition and amount of carbohydrates and fats as well as optimal gestational weight gain and energy restriction (Uplinger, 2009). Both the ADA and CDA do nonetheless suggest that nutritional counseling be offered by a registered dietitian to ensure that the prescribed meal plan promotes euglycemia, appropriate weight gain as well as adequate nutritional intake (ADA, 2007; CDA, 2008). The CDA also states that meal planning should emphasize only moderate carbohydrate restriction over the course of three meals and three snacks per day. They also caution against hypocaloric diets. Even in cases of high pre-pregnancy body mass, energy restriction is not recommended as it can result in weight loss or ketosis, as well as providing inadequate amounts of key nutrients such as protein and calcium (CDA, 2008).

Dieticians of Canada (DC) recently made dietary recommendations for GDM, concluding that nutrition requirements are similar to those for non-diabetic pregnant women (Anderson et al., 2006). Although others have stated there was often little evidence to support most recommendations (Boinpally and Jovanovic, 2009; Gunderson, 2004; Uplinger, 2009), the group put forward nine recommendations (see Table 2.2).

**Table 2.2: Recommendations for Nutrition Best Practices for Women with GDM**

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1. Nutrition counseling by a registered dietitian
  2. Total weight gain and energy intake should take pre-pregnancy BMI into consideration and energy intake for overweight or obese women may be restricted
  3. Type and amount of carbohydrate should be individualized, with total mixed carbohydrate making up 40-45% of total energy
  4. Distribution of carbohydrate should be individualized and adjusted based on clinical parameters but generally distributed throughout the day over 3 meals and 2 to 4 snacks
  5. Artificial sweeteners other than saccharin and cyclamates are considered acceptable during pregnancy
  6. Fat should only comprise up to 40% of total energy during pregnancy, with consideration given to the type of fat consumed
  7. Vitamin and mineral supplementation are similar to requirements for pregnant women without GDM
  8. Physical activity should be encouraged and individualized to reflect obstetric risks
  9. Use of CDA guidelines and professional judgment in the provision of individualized care
- 

(Adapted from Anderson et al., 2006)

**Pharmacological interventions.** If glycemic targets are not achieved within two weeks with nutrition therapy alone, the CDA recommends that insulin therapy be initiated (CDA, 2008). The ADA and ACOG give specific glycemic targets that are necessary to achieve prior to beginning insulin therapy. These levels are similar to the CDA glycemic targets listed in Table 2.1, but slightly higher overall at: 5.0 – 5.5 mmol/L FPG, and 6.65 to 7.05 mmol/L 2hPG (ACOG, 2001). Insulin therapy is currently the only recommended medicinal treatment for GDM. The majority of oral antihyperglycemic agents are thought to cross the placenta and simulate hyperinsulinism and pose risk of fetal anomalies (Jovanovic, 2004; Koren, 2004). Recent evidence suggests that blood glucose levels rather than the drugs themselves may be responsible for those adverse outcomes reported (Langer et al., 2000). As of result of this study, oral antihyperglycemic agents are gaining recognition as a safe and effective alternative to insulin therapy for women with GDM (Jovanovic, 2004; Koren, 2004; Langer, 2002). However, both the ADA and CDA appear

to be reserving judgement on this issue until further studies are conducted (ACOG, 2001; ADA, 2009; CDA, 2008; Paglia and Coustan, 2009).

**Exercise.** Moderate exercise is believed to play an important role in lifestyle interventions aimed at minimizing the potential complications of GDM. Current CDA guidelines suggest that physical activity should be encouraged unless contraindications exist or glycemic control is made worse by the activity (CDA, 2008). Recommendations from the fifth International Workshop-Conference on Gestational Diabetes Mellitus advocate for daily planned physical activity of at least 30 minutes for all women capable of participating and suggest activities such as brisk walking and seated arm exercises (Metzger et al., 2007). There are, however, gaps in the literature that Dietitians of Canada feel limit the ability to definitively link exercise with blood glucose control and risk or benefit to infants. They recommended, as listed in Table 2.2, that physical activity should be encouraged in the management of GDM, but any exercise program should be individualized to take obstetrical risks, exercise tolerance and preferences into consideration (Anderson et al., 2006).

Randomized trials of exercise training in GDM have suggested a role of maternal exercise in the safe treatment of GDM (Jovanovic and colleagues, 1989; Avery and Walker, 2001; Bung and colleagues 1991 and 1993). More recent Canadian studies have shown favourable trends in the reduction of excessive weight gain observed among women at risk of developing GDM (Brankston et al., 2004; Hui et al., 2006). Larger trials such as the “FitFor2” study in the Netherlands and the B.A.B.Y study in the U.S. are

currently underway and both were designed to look at the prevention of GDM through exercise (Chasan-Taber et al., 2009; Oostdam et al., 2009).

### **Maternal and Fetal Outcomes**

**Maternal outcomes.** One of the most serious maternal outcomes of GDM is a lifetime risk of type 2 diabetes. Although the majority of pregnant women develop some degree of insulin resistance during pregnancy, those with gestational diabetes are slightly more insulin resistant during late pregnancy (Xiang et al., 2000). Postpartum, women with GDM may continue to have quantitative defects in insulin secretion, relative to their degree of insulin resistance. Therefore, the fraction of women at risk for diabetes after GDM is high, particularly if they are overweight (Buchanan and Kjos, 1999; Yogev and Visser, 2009). A recent meta-analysis of follow-up studies also revealed that women who have had GDM also have at least a seven-fold increased risk of developing type 2 diabetes in the future, compared to their normoglycemic counterparts (Bellamy et al., 2009). Women with a history of GDM are also at an increased risk of developing cardiovascular disease (King et al., 2009).

**Perinatal outcomes.** Infant macrosomia, or excessive fetal growth, however, is the most frequently cited indicator of adverse perinatal outcome linked with gestational diabetes. Both clinical and experimental evidence support a connection between hyperglycemia and the development of fetal macrosomia (Kwik et al., 2007; Persson and Hanson, 1998; Pettitt et al., 1980; Schwartz et al., 1994; Stone et al., 2003). Studies testing the effects of intervention treatments for GDM compared to control groups have



shown that rates of macrosomia are significantly lower among those women treated for hyperglycemia (Adams et al., 1998; Naylor et al., 1996; Sermer et al., 1998). Other potentially adverse perinatal outcomes, such as increased rates of cesarean section, shoulder dystocia, asphyxia and other birth traumas tend to be associated with macrosomia (Bennett, 1999; Ray et al., 2001; Stone et al, 2002). A recent investigation in Manitoba that examined the impact of GDM on maternal fetal outcomes found elevated rates of macrosomia among mothers with GDM with an overall incidence of 15.3%. Rates of stillbirth, cesarean section and shoulder dystocia (SD) were reported at 0.57%, 16.0% and 1.2% respectively. Increased stillbirth rates were, however, associated with First Nation status and increased age (Aljohani et al., 2008b).

Other infant metabolic complications associated with GDM that have been less frequently reported in the literature include: hypoglycemia, polycythemia, hyperbilirubinemia and respiratory distress (Oh, 2004; Rodrigues et al., 1999b; Weindling, 2009). Like congenital malformations, these outcomes tend to be associated with a type 2 or type 1 diabetic pregnancies. In an effort to more conclusively assess any specific association between less severe hyperglycemia and adverse pregnancy outcomes, however, the HAPO study focused on morbidities most strongly associated with the maternal metabolic disturbances of GDM. The study group has determined thus far, that even slightly elevated maternal blood glucose levels are associated with fetal hyperinsulinemia, increased weight at birth, higher rates of caesarean deliveries, and neonatal hypoglycaemia (HAPO, 2008). There, however, remains a paucity of

information on the optimal maternal glucose levels aimed at reducing embryonic, fetal and perinatal morbidity without negatively impacting intra-uterine development (Eriksson, 2009).

**Long-term infant outcomes.** As knowledge increases about the long-term implications of a diabetic intrauterine environment, the mother's fetal and familial history have become characteristics that could predict her, or her child's subsequent risk of GDM. A study in Norway, for example, using data linkage from the national birth registry found that women whose mothers had been diagnosed with GDM were at increased risk. Inverse trends in diabetes were also discovered in relation to birthweight, with risk of GDM elevated in women with lower birthweights (Egeland, 2000; Pettitt and Knowler, 1998). This prediction, otherwise known as the "Barker Hypothesis" suggests that low birth weight as a result of poor intrauterine growth predicts the subsequent development of physiological disturbances in adult life, such as the development of impaired glucose tolerance, insulin resistance and type 2 diabetes (Hales et al., 1991).

Abnormal glucose tolerance or metabolic changes may therefore be more common in offspring of diabetic women. Potentially, impaired glucose tolerance and diabetes mellitus can result and may commence at an earlier age (Dabelea et al., 2004). Dabelea and colleagues have studied the influences of the maternal environment extensively through their continued work with the Pima of Arizona. As many as 70% of offspring exposed to diabetes in utero developed type 2 diabetes during their late 20s and early 30s (Dabelea et al., 2000). A follow-up study of children of diabetic Pima Indian women provide some of the most informative data on this subject, revealing as well that the

offspring of diabetic women tend to be larger for gestational age at birth (Pettitt et al., 1983). Normal birthweight offspring of diabetic women were also heavier overall from the ages of 5 until 19 than the children of nondiabetic or pre-diabetic<sup>1</sup> women (Pettitt et al., 1987).

## **The Experience of Diabetes**

**Diabetes and Aboriginal peoples.** The World Health Organization (WHO) estimated that over 150 million people had type 2 diabetes in 2000. By 2025 this figure is predicted to top 380 million (CDA, 2008). Given these dramatic estimates, along with recent literature on the status of the situation among Canadian Aboriginal groups diabetes is considered to have reached epidemic proportions (Dyck et al., 2010; Joe and Young, 1993; King et al, 1998; Young et al., 2000). In Canada, age-adjusted prevalence rates are three to five times higher for Aboriginal people, compared to other Canadians (CDA, 2008). Reported prevalence rates for GDM are also higher and range from 11.5 to 14.9% among groups of Aboriginal women in Canada compared to 3-5% in the overall population (Aljohani et al., 2008a; Brennand et al., 2005; Dyck et al., 2002; Godwin et al., 1999; Harris et al., 1997; Rodrigues et al., 1999). In the U.S., rates as high as 15.3 % have been published among Zuni women (Benjamin et al., 1993) compared to between 1.1 - 14.3% among other women in general (LaVallie et al., 2003). An Australian study similarly concluded that GDM prevalence is consistently and significantly higher among Aboriginal communities in both Australia and New Zealand with prevalence rates of

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<sup>1</sup> Used in this context to mean women with normal glucose tolerance during pregnancy who subsequently develop type 2 diabetes.

6.3% and 7.9% respectively (Simmons et al., 1999). The overall GDM rate for Aboriginal women is also currently reported to be more than 2.5 times higher than for non-Aboriginal women (Ishak and Petocz, 2003).

For both Aboriginal and non-Aboriginal populations, type 2 diabetes mellitus is by far the most common form of diabetes, making up 90% of cases. Type 2 diabetes typically occurs among persons who are approaching middle age, are overweight, have a sedentary lifestyle and a family history of the disease. Aboriginal identity has also been associated with increased risk (CDA, 2008; Dyck et al., 2010; Ferreira and Lang, 2006; Rock, 2003; Waldram et al., 1995; Young et al., 2000), which has launched a vigorous debate to isolate and explain the causes of this relatively recent epidemic. Many of the biological and other lifestyle-associated risk factors for type 2 and gestational diabetes discussed in the epidemiological literature continue to be based upon biomedical theories developed in the 1960s and 1980s (Ferreira and Lang, 2006; Park, 2004). The extent and magnitude of diabetes among “high risk” Aboriginal populations is known to vary widely across cultural, geographical and socioeconomic groups (Young et al., 1990; Young, 1994), yet many causation theories are based in a genetic determinism of diabetes that does not sufficiently answer the question why Aboriginal groups, women in particular, suffer such a disproportionate amount of this burden (Ferreira and Lang, 2006; McDermott, 1998).

Perhaps partly because the lived experience of distress is not acknowledged as a public health problem in its own right, it has not received as much attention as it necessarily deserves in relation to the rising pandemic of diabetes in Aboriginal

populations. Mental or spiritual health issues have yet to appear on lists of common diabetes risk factors (Rock, 2003), but as Walters and Simoni (2002) have acknowledged, precisely how historical and current traumas affect the health of Aboriginal populations may be challenging to document empirically. A growing literature, however, reflects a research direction towards understanding the relationship between perceived stress and/or experienced trauma and diabetes (Dinges and Joos, 1988; Ferreira, 2006; Iwasaki et al., 2004; Scheder, 1988). Qualitative research studies, in particular, are building a better understanding of diabetes as a product of life experience, based on the long-time efforts of mainly medical anthropologists, such as Garro (1988; 1995; 1996), Lang (1985, 1989), Scheder (1988), and Scheper-Hughes (1992).

Among Aboriginal groups, Benyshek (2002) has commented that Native American populations at greatest risk for developing type 2 diabetes are the ones which have endured the most extreme and extended periods of political and economic oppression (cited in Scheder, 2006). Jo Scheder published a seminal article in 1988 relating diabetes to macro-level politics and economics. She was able to demonstrate neuroendocrine and experiential linkages between social inequality and diabetes among Mexican-American migrant farmworkers in Wisconsin. More recently, medical anthropologist Mariana Ferreira published a paper based on a combination of quantitative and qualitative components to similarly demonstrate that persons who have experienced a major traumatic event have a much higher probability of developing type 2 diabetes thought to be because of emotional suffering (Ferreira, 2006). The quantitative component of her study on a Yurok reservation in northern California revealed what

Scheper-Hughes has termed “consequences of genocide and its aftermaths” as diabetes is viewed as a socio-political pathology in the signature that collective losses have left on the bodies, physiologies and chemistries of Aboriginal peoples (2006; p. xviii).

Associations between oppression, colonialism and diabetes were statistically supported in a genealogical analysis of 20 of extended Yurok families tracing a history of abuse, confinement, discrimination and traumatic memory.

A “stress-strain” hypothesis was similarly proposed by Garrity and colleagues in 1977. They suggested that psychophysiological strain mediates the impact of life events. The hypothesis also reflects the theory that certain self-esteem threatening life events will tend to elicit a typical response pattern, such as a “helpless/ hopeless” reaction. For some individuals, the authors argue, in the presence of either an environmental pathogen or physiological vulnerability, could lead to illness (cited in Dinges and Joos, 1988). The hypothesis also describes the concept of “surrender”. Ethnographic interviews conducted with a Pima community on the topic of diabetes suggests this concept as Kosak describes it as: “an emotion whereby individuals and a segment of the community feel unable to control what they perceive as an inevitable fact of life that lies outside of their direct influence” (Kosak, 1997; p. 349). For Pima, a hypothetical life history of themselves has been created where they emotionally expect to become diabetic and die from diabetes because it is their life experience and hence reality (Kosak, 1997). In other words being Aboriginal means you will eventually get diabetes.

Other authors have exclusively used qualitative research methods to examine the life experience of diabetes. Garro and Bruyère, for example, used Arthur Kleinman’s

explanatory model framework (Kleinman, 1978) in Manitoba Aboriginal communities with Aboriginal women and men previously diagnosed with type 2 diabetes (Bruyère, 2000 and 2006; Garro, 1995 and 1996). Bruyère described a number of factors that members of a northern Cree community associated with the etiology and onset of the disease. As the nature of diabetes is described in their language, sugar was identified as one of the causes of the illness. Recent environmental disruptions including pollution as a result of hydroelectric development were also viewed as having contributed to rising rates of type 2 diabetes in the community. Many felt these rapid changes to the land had adversely affected the way of life in the community, leading to loss of traditional foods and a subsequent reliance on store-bought or fast foods.

In other First Nation communities in southern Manitoba, Garro encountered similar perceptions surrounding the role of food in health (Garro, 1995). Participants in her study generally attributed the onset of type 2 diabetes to certain types of food. For example, many said too much sugar, alcohol, fat and being overweight could result in diabetes. Store bought foods, such as processed, “junk”, or canned foods were described as being particularly unhealthy. Individuals also discussed the gradual change in eating habits since the introduction of these unhealthy contemporary foods, which were generally perceived as being of an inferior quality compared to wild foods. Sickness, such as diabetes was not associated with diets long ago that mainly consisted of culturally familiar foods. Garro’s studies also used cultural consensus analysis to determine shared cultural knowledge for the three participating communities (Garro, 1996), however, there was considerable variation reported with two alternative models of diabetes causation

described by participants (Garro, 1995). Referred to as the “contaminated food model”, the first position implied a broader social context of the disease compared to the “biomedical teachings model” that represented views participants associated with the teachings of health professionals.

Although not using the explanatory model framework, results from the ethnographic work of Gretchen Lang were similar to Linda Garro’s studies in Manitoba. Lang also described food beliefs associated with type 2 diabetes that were collected from a Sioux community in North Dakota (Lang, 1985). Participants described a collective understanding of diabetes, with diabetes treatments often impinging on more traditional or customary food beliefs. Modern foods, such as canned and store bought foods were identified as being “unhealthful” by the community members, compared to more traditional foods that hold much higher cultural esteem or status. According to Lang, “traditional foods and medicinal plants and wild game represent purity, healthfulness and strength - symbols of a pre-reservation (and pre-European) life and culture” (Lang, 1989; p.310).

The exclusivity of biomedical messaging in diabetes treatment and management does not take into account socially produced or naturally occurring risks. The ability to manage diabetes is considered a reflection of the ability of the self to be successful and failure therefore implies shame (Sunday and Eyles, 2001). Sunday and colleagues (2001) have argued that diabetes is a collective problem and that lifestyle choice should not be blamed on individuals. For Aboriginal groups they are related to macro-political forces as well. By blaming the individual, a biomedical perspective excludes the broader social



context of the disease” (Garro, 1995). There are social consequences in addition to the more overt or visceral complications of diabetes. Aboriginal participants from other studies in Ontario and Manitoba have referred to the social rather than the physical consequences of diabetes and describe feeling “ashamed” of their diabetes. Negative perceptions associated with diabetes significantly add to their levels of stress and contribute to their physical, emotional, social and cultural isolation (Gregory et al., 1999; Iwasaki et al., 2004 and 2005; Lautenschlager and Smith, 2006; Sunday and Eyles, 2001).

**Women’s experiences with gestational diabetes.** On the topic of women’s experiences with GDM, very few qualitative studies have been published. Only a handful of qualitative studies have taken place with non-Aboriginal groups in Canada, the U.S. and Europe (Evans and O’Brien, 2005; Hjelm et al., 2005; Hjelm et al., 2006; Kieffer et al., 2002; Lawson and Rajaram, 1994). Fewer still have included Aboriginal women. Smith-Morris is the only other author to my knowledge to have conducted a qualitative study on Aboriginal women’s experiences with diabetes during pregnancy. She interviewed Pima women in Arizona. The way women respond to and think about GDM, she suggested provides insight into their health seeking patterns and reactions to diabetes screening or prenatal care. She noted, “the biomedical perspective, not homogeneous itself, exists simultaneously with varying local perspectives on this disease” (Smith-Morris, 2005; p. 146). Her results discussed the possibility, for example, of Pima women delaying prevention behaviours since they perceived GDM to be a “work in progress” without definitive definition or necessarily negative associations (Smith-Morris, 2005; p.164). Many women discussed gestational diabetes as “symptomless” (Smith-Morris,

2006a; p. 195) and therefore not necessarily a disease that can be prevented. Pima women similarly questioned the long-term effectiveness of prevention behaviours because of the continuing high incidence and prevalence of diabetes in their communities (Smith-Morris, 2006a).

According to Smith-Morris (2005), there was little understanding of Aboriginal women's experiences and perceptions of pregnancy and how they may or may not influence her prenatal attendance or participation in other community-based efforts. She has found that longer conversations between maternal care providers and patient may be beneficial to improve not only compliance, but communication as well. The inclusion of family members in prenatal programming may also assist in these respects. As Humphrey (2006) has also suggested, health professional often do not recognize of the everyday socioeconomic factors such as poverty, unemployment, overcrowding, lack of housing, lack of access to transportation, and poor educational opportunities. These factors may be underlying issues such as 'patient non-compliance' when it comes to dietary and other lifestyle diabetes prevention measures.

Discussions of gestational diabetes by Pima women were also influenced by biomedical, traditional and popular notions (Smith-Morris, 2006a). Those who had completed prenatal education classes where diabetes education was provided, more readily adopted biomedical explanations for GDM. Information transferred by care providers during prenatal appointments was found to be the most influential with regard to women's perceptions and interpretation of messages relayed (Smith-Morris, 2005). However, for women living on the reservation, a primarily monocultural rural setting

where type 2 diabetes is endemic, there is perhaps greater opportunity to develop more collective banks of experience or memory in a social context that may or may not be aligned with biomedical accounts of diabetes (Smith-Morris, 2005). For Pima women, diabetes is conceptualized primarily in terms of its most visible complications such as blindness and amputations. Diabetes also increases young women's sense of vulnerability to the disease as well as their level of frustration with care providers who were not precise or reliable in the risk information provided (Smith-Morris, 2005; Smith-Morris, 2006a).

Non-Aboriginal women who have been diagnosed and treated for GDM may experience psychosocial effects associated with the diagnostic label. Poor overall health perception has been linked with GDM diagnosis, in addition to increased anxiety regarding fetal health (Kerbel, 1997; Laplante, 1992). In an ethnographic study of gestational diabetes, Lawson and Rajaram (1994) found the emotions women attach to the disorder include anxiety, depression and fear. Complying with various treatment programs, such as dietary interventions, and more frequent interactions with health care professionals also added stress to the 'normal' experience of pregnancy. Perinatal depression among low-income new mothers has also been recently investigated. Women with diabetes (prediabetes and GDM) had nearly twice the risk of a depression diagnosis compared to those without diabetes, even after adjusting for age, ethnicity, gestational age at birth and year of delivery (Kozhimannil et al., 2009). Women with GDM participating in a randomized clinical trial who received preventative counseling during their pregnancies reported lower rates of depression postpartum (Crowther et al., 2005).

Participants in Evans and O'Brien's (2005) Canadian study described their diagnosis of GDM as shocking and something that was not anticipated. It threatened their autonomy and sense of control over their lives, although it was not necessarily associated with the severe complications Aboriginal women describe. The mainly culturally homogeneous women in the study were motivated to take appropriate actions in managing their GDM because many felt blamed or responsible for developing diabetes while pregnant. Physical symptoms were also intangible which left women feeling anxious and vulnerable. Additional instability and confusion were reported because of the perceived imprecise nature of prenatal tests and education messages regarding outcomes. For some women having GDM presented a negative stigma that was embarrassing as it signified they were unhealthy. Living with GDM altered these women's views of their health status to the extent they were motivated to make lifestyle changes. According to one participant, she felt "*empowered*" by the experience and gained confidence to make choices that would enhance her long-term health (Evans and O'Brien, 2005; p. 74).

Other studies among U.S. and European women have similarly described an intense emotional reaction to a diagnosis of gestational diabetes (Hjelm et al., 2006; Lawson and Rajaram, 1994). GDM was referred to as "elusive" with nulliparous women feeling especially anxious about their lack of preparation, knowledge and absence of physical symptoms (Hjelm et al., 2005; Hjelm et al., 2006; Lawson and Rajaram, 1994; p. 544). Stress and worry coupled with self-blame were also noted for a group of women in Kentucky. They expressed confusion as to the etiology of GDM, yet were aware of its potentially serious outcomes. Similar to the Canadian study, this mainly culturally

homogeneous group found the motivation to make changes in lifestyle as a positive consequence of their diagnosis, even though it had negative effects overall on their self-esteem (Lawson and Rajaram, 1994).

Middle-Eastern and Guatemalan immigrants who were interviewed in Sweden and Detroit, Michigan described similar experiences with GDM. Both groups of women referred to a social isolation adjusting to life in a culturally foreign urban centre. Many were separated from families and extended support networks, with small children to care for at home (Hjelm et al., 2005; Hjelm et al., 2006; Kieffer et al., 2002). Middle-Eastern women had less self-perception of bodily symptoms as well as a lower degree of self-efficacy compared to Swedish women with GDM. They also discussed social factors more frequently as being important for the health of mother and baby, such as emotional support from healthcare providers and family members. Swedish women talked about the importance of individual factors such as exercising and eating a healthy diet and did not accept the condition of GDM as chronic. They actively searched for information to prevent the development of type 2 diabetes (Hjelm et al., 2005).

Kieffer and colleagues (2002) suggest that beliefs about etiology, personal susceptibility and modifiability of risk when it comes to diabetes, may all influence women's motivation to undertake lifestyle changes. The degree of perceived control of self-efficacy for these groups of minority women with GDM may also be related to a higher perceived susceptibility to and severity of diabetes, as well as a higher awareness or risk. Migrational, transitional or stressful life experiences, it has been suggested, may negatively impact the sense of control women have over their lives and health status

(Hjelm et al., 2003). These circumstances may be most challenging for Aboriginal women with GDM who feel stigmatized or further marginalized by their condition. Life experiences and perceptions are, however, particularly relevant in attempts to manage and control an often symptomless condition like GDM (Smith-Morris, 2006a). Other qualitative investigations have drawn similar conclusions and consistently called for the creation of peer groups for social support for those coping with GDM (Evans and O'Brien, 2005; Hjelm et al., 2004; Hjelm et al., 2006; Kieffer et al., 2002; Smith-Morris, 2005) and type 2 diabetes (Barton et al., 2005; Daniulaityte, 2004; de Alba Garcia et al., 2007; Gregory et al., 1999; Skelly et al., 2006).

### **Literature Summary**

As described in this chapter, gestational diabetes mellitus is evolving as a clinical entity. Controversy continues to exist in a vast number of areas, most notably in its definition, detection and epidemiology. Because of these issues, it is difficult to make direct comparisons among studies and the true incidence of GDM may be unknown. Determining the extent of global increases in GDM is therefore difficult, although there is general agreement in the scientific literature that rates are on the increase.

The most commonly cited risk factors for gestational diabetes are increased maternal age, weight, parity, previous delivery of a macrosomatic infant and being a member of a "high risk" population group, such as Aboriginal women. It is mainly those unmodifiable risk factors that are used to identify and screen women with the greatest potential to develop GDM. An internationally unified approach in the screening and diagnosis of women with gestational diabetes, however, remains fragmented even with

the conclusive results of the 2008 HAPO study that concluded even slightly elevated hyperglycemia during pregnancy poses significant health risk to mother and child. Current CDA Clinical Practice Guidelines are the only recommendations in North American that advocate universal screening for all women between 24 and 28 weeks gestation. Those with multiple risk factors are to be screened during the first trimester (CDA, 2008).

Once a diagnosis of GDM has been confirmed, there also exists a wide range of opinion regarding the lifestyle and pharmacological treatments. Specific dietary guidelines are inconsistent given the lack of evidence for an optimal diet, particularly regarding carbohydrate intake and optimal gestational weight gain. Insulin therapy is currently the only recommended treatment for GDM if glycemic targets are not achieved within two weeks of initiating nutrition therapy. Moderate exercise is also believed to play an important role in lifestyle interventions aimed at minimizing the potential complications of GDM.

Women with a history of gestational diabetes are more at risk of developing type 2 diabetes in the future, as well as cardiovascular disease. Their infants are more likely to be macrosomatic and therefore experience other potentially adverse perinatal outcomes such as increased rates of caesarean section, shoulder dystocia, asphyxia, as well as other infant metabolic conditions such as hypoglycaemia at birth. Longer term outcomes for children of mothers with GDM include elevated rates of obesity and the development of type 2 diabetes at an earlier age.

Prevalence rates for type 2 and gestational diabetes are much higher among Aboriginal versus non-Aboriginal populations. In relation to the rising this epidemic among Aboriginal women in particular, the lived experience of diabetes has not received as much research attention. A growing literature is building a more detailed understanding of type 2 diabetes as a product of life experience, with some authors suggesting that Aboriginal populations who have endured the most extreme and extended periods of oppression are at greatest risk for developing diabetes. Few authors have used qualitative methods to describe Aboriginal men and women's experiences with type 2 diabetes. Existing research mainly discusses the role of food in health and the etiology of diabetes as well as the social consequences and negative perceptions associated with the disease.

There have been even fewer qualitative investigations into the experiences of women with gestational diabetes. Smith-Morris is the only author to conduct a study among Aboriginal women. Her results provide insight into Pima women's health seeking patterns and reactions to diabetes care. Since diabetes in the community is often conceptualized by its most visible complications, this may increase pregnant women's sense of vulnerability and frustration with conflicting education messages on risk associated with GDM. Non-Aboriginal women with GDM, overall associate poor health with their diagnosis and tend to attach negative emotions to their condition such as stress, anxiety, depression and fear. These life experiences and perceptions of GDM are particularly relevant in attempting to manage and control this often symptomless condition that poses multiple risks to mother and child.



In pursuing research that will explore the experiences of Aboriginal women with GDM in the context of Winnipeg, Manitoba, the next chapter will include the theoretical and methodological frameworks that were used in conducting the study. I will describe the research process and qualitative methodologies that were employed in detail, in addition to the theoretical orientations chosen in approaching the research topic and those that assisted overall in guiding the study.

## Chapter Three

### Theoretical and Methodological Frameworks

In this chapter I describe the theoretical and methodological frameworks used in approaching the overall study: Arthur Kleinman's Explanatory Model Framework and Cultural Consensus Theory. The concept of incorporating Indigenous epistemologies or perspectives into the research process will then be presented, as well as the implications of attempting to traverse this ideological divide that exist between Indigenous world views and Western science. After describing the research process, including the overall study design, participant recruitment and analysis, I conclude this chapter with a discussion of the limitations and implications of the methodological process.

#### Theoretical Orientation

**Explanatory model framework.** Smith-Morris (2006) recommends paying close attention to Indigenous forms of producing knowledge. The elicitation of stories through the process of open-ended interviewing, according to Smith (1999), Simpson (2000), Mill (2000) and Barton (2008), is concordant with Aboriginal groups whose stories, history and culture are based in oral tradition and experiential forms of knowledge transmission. Life experiences and perceptions recounted orally as modes of communication may develop a more holistic account in chronicling Indigenous cultural understandings of the meanings of risk or prevention strategies for Aboriginal women with gestational diabetes mellitus (GDM).

Professional understandings of health tend to focus on the disease process, whereas the personal or lay experience of illness is often more complex in meaning

(Sunday et al., 2001). As a theoretical orientation to guide the interview process, the explanatory model framework (Kleinman et al., 1978) was utilized to conceptualize and understand Aboriginal women's experiences with gestational diabetes. The theoretical assumption underlying this model is that people incorporate understandings as well as experiences into cultural frameworks and symbolic systems of meaning. As Kleinman states, "the model is an attempt to understand health, illness and healing in society as a cultural system" (Kleinman, 1978; p.85). Illness is culturally shaped in terms of how one perceives, experiences and lives with the condition or disease based on one's own explanations of sickness, which tend to be specific to one's position in society and systems of meanings used (Kleinman et al., 1978). Explanatory models (EMs) are therefore subjectively and personally constructed, thereby reflecting the culturally situated meanings of an illness. In contrast to the field of clinical medicine which tends to view disease biologically, EMs incorporate the psychological and cultural aspects of the illness from the patient's perspective (Kleinman et al., 1978; Meeto and Meeto, 2005). These frameworks are viewed as cognitive beliefs created to recognize and respond to a specific illness experience, thereby potentially assisting with an individual's ways of coping and making sense of one's changing state of being (Kleinman, 1980).

Explanatory models generally contain explanations of five issues that help to inform the interview process and aid in the interpretation of results (Kleinman et al., 1978). The open-ended questions developed to guide the semi-structured interviews were framed around the five themes of etiology, onset, pathophysiology, course of sickness and treatment. The wording of the questions can vary depending on the participant's characteristics, her illness, and the interview setting. Other questions are suggested that

may help to elicit therapeutic goals and other psychological or cultural meanings surrounding the illness such as: the most important results hoped for from treatment; main problems the illness has caused, and greatest fears of the patient (Kleinman, 1980). A sixth theme was added for this study: prevention. Arcury and colleagues (2004) have suggested explanatory models are compatible and sufficiently flexible to incorporate the addition of themes or concepts of wellness and diabetes prevention.

This methodology has been used mainly by medical anthropologists to work towards a better understanding of health practices and behaviours in a number of cultural settings including among Indigenous or Aboriginal groups (Arcury et al., 2004; Bruyère, 1998 and 2006; Bruyère and Garro, 2000; Garro, 1988 and 1995; Jezewski and Poss, 2002; Lang et al., 2004; Meetoo and Meetoo, 2005; Mill, 2000; Poss and Jezewski, 2002; Sunday et al., 2001; Thompson and Gifford, 2000). A wide range of illnesses have been examined through these investigations; they differ as to the degree of rigidity to which they adhere to the methodology as well as the variety of cultural participation. The illness experience of type 2 diabetes, for example, has been studied among Canadian (Bruyère, 1998 and 2006; Bruyère and Garro, 2000; Garro, 1995; Sunday et al., 2001) and Australian (Thompson and Gifford, 2000) Aboriginal groups, as well as in Asian, Caucasian (Meetoo and Meetoo, 2005) and Latin American communities (Arcury et al., 2004; Jezewski and Poss, 2002; Poss and Jezewski, 2002). Human immunodeficiency virus (HIV) illness and high blood pressure have also been investigated among Canadian Aboriginal groups (Garro, 1988; Mill, 2000).

These primarily anthropologic and sociologic studies distinguish and contrast between the concepts of disease and illness (Kleinman, 1988). Disease being a primarily

Western medical paradigm focusses on the “malfunctioning or maladaptation of biologic and psychophysiologic processes in the individual” as compared to the idea of illness (Kleinman, 1980; p.252). Illness tends to be shaped by cultural factors which govern the perception, labelling, explanation and valuation of the experience (Kleinman, 1980 and 1988). Although the concepts of ‘culture’ or ‘cultural sensitivity’ have been considered to be somewhat reductionist in perspective (Browne and Smye, 2002; Gray and Thomas, 2006; Ferreira and Lang, 2006; Smith, 1999), the intent and applicability of explanatory models are reflexive and holistic. Kleinman himself defines culture as a “system of symbolic meanings that shapes both social reality and personal experience” thereby mediating between external and internal parameters (1978; p.86).

Authors such as Allan Young (1981) have also criticized explanatory models as being narrow, postulating that they tend to focus on cognitive reasonings thereby excluding other more emotional or personal dimensions of sickness and healing. Singer (1995) has also noted they often fail to address the social, economic and political causes of illness or their influences on personal illness experiences. Kleinman (1981) does not dispute these points and stresses that researchers and clinicians working within this framework should be cautioned against introducing causal logic into conceptual schemas, thereby potentially excluding other important intrapsychic and interpersonal dimensions. Explanatory models are appropriate for trying to understand Aboriginal women’s explanations of gestational diabetes, the goal of this study.

**Cultural consensus theory.** Although rich in their descriptions, the open-ended responses derived from qualitative interviews are difficult to compare on their own. It is also often challenging to address the issue of intra-cultural variation in qualitative

research because it can be difficult to make specific comparisons (Daniulaityte, 2004). Cultural consensus theory provides a way for ascertaining whether or not shared cultural understandings exist within a community or group (Romney et al., 1986). It is based on the assumption that people share perceptions about their world, and that agreement or disagreement in such understandings is patterned and can therefore be measured (Garro, 1988). If shared understandings are determined, the theory permits comparisons between individuals, or groups of individuals, to more accurately evaluate patterns of similarities and differences within social or cultural groups (Garro, 1996).

While people tend to make statements based on individual knowledge, much of this knowledge can be attributed to cultural sharing. Garro (1988) refers to this shared knowledge as *cultural understandings*. Cultural consensus theory allows for an examination of individual differences in their cultural understandings. Cultural consensus analysis (CCA) estimates the degree to which each participant's discussions represent shared knowledge on a given topic or domain (Garro, 1996). The method permits cultural knowledge to be measured and its group distribution described mathematically (Romney et al., 1987). The mathematical model originated from reliability testing theory. In reliability testing, the focus is on the test's ability to predict a score that describes an individual; for example, a spelling test predicts one's ability to spell. Cultural consensus theory would be used in this case to predict the words' correct spelling (Weller and Romney, 1988), because participants who do not know the correct answer give a variety of wrong answers, while those who know the correct answer give the same correct spelling. If there is a correct answer, and people know and give it, it will be evident in the pattern of responses.

The CCA technique developed by Romney, Weller and Batchelder (1986) estimates how much each participant “knows” about the domain being studied. In CCA it is assumed that the correspondence between any two participants is a function of the extent that each has knowledge of the culturally “correct” or shared answers (Weller and Romney, 1988). Those participants who are most knowledgeable are therefore expected to respond more closely to each other than those with less knowledge on the research topic. In estimating how much each participant knows within a cultural domain, each answer is weighed and aggregated to estimate the most likely answers. Consensus analysis then predicts the reliability of the information content of the responses, ultimately testing the pattern of agreement or consensus among those interviewed, thereby making inferences about the “correct” answers to the questions (Weller and Romney, 1988). The assumptions underlying the model include that there is a single shared answer to each question. If it is known by the participants, that answer is given. The second assumption is the questions are independent of each other, and are responded to independently. The third assumption states that all of the questions are derived from the same cultural domain (Romney et al., 1986).

The group of Aboriginal women participating in this study did not constitute a formalized community or group, so cultural consensus theory was useful to determine whether or not aggregate responses collected from the participants could be directly compared. If shared cultural knowledge is determined through cultural consensus analysis, the theory permits comparisons between women to more accurately evaluate the degree of concurrence or convergence of response (Garro, 1996). Cultural consensus also potentially allows for a greater understanding of individual differences in shared

knowledge and can provide the basis for a contextual framework within which to further interpret responses from less structured interviews.

On its own, cultural consensus theory determines only whether or not shared knowledge exists between communities or participants. Therefore, cultural consensus is not meaningful unto itself (Garro, 1988). Garro (1996) recommends combining this method with patterns emerging from open-ended interviews to “illuminate the consensus analysis” (p. 383). The mathematical model also complements open-ended interviews with the systematically collected data facilitating comparisons. Only a small number of participants is necessary to reliably predict the culturally accepted responses since reliability of aggregated responses is not just a function of sample size, but is also a function of the agreement among participants (Weller and Romney, 1988).

The use of cultural consensus analysis combined with an open-ended explanatory model interview format were used to explore Aboriginal women’s understandings and experiences of GDM and provide a more comprehensive understanding of how Aboriginal women in Winnipeg think about their condition than would have been possible through the use of one single theoretical approach. Using the two interview formats together preserved the focus on Aboriginal women’s perspectives while at the same time providing a statistically valid way to assess how widespread their ideas and experiences are (Marchessault, 2001). Including the fixed-response statements used with consensus analysis also gave the participants the opportunity to respond to issues that they might be familiar with but did not raise independently during the open-ended or semi-structured interviews (Garro, 1996). Garro’s work in this area, according to Wiedman, has refined anthropological research methods and is considered the



“foundation for understanding Indigenous medical knowledge, practices and decision-making” (2006; p. 518). Garro (1995, 1996) used both explanatory model interviews and CCA to examine cultural understandings in causal accounts of type 2 diabetes among three Canadian Anishinaabe communities. Using two kinds of interview formats, she was also able to determine agreement and variation both within and between communities (Garro, 1996). Marchessault (2001) similarly examined Aboriginal women’s and girls’ understandings of weight issues among different age, community and cultural groups using in-depth interviews and CCA.

Cultural consensus analysis has also been previously used to assess intracultural variation in a number of other settings in a variety of domains ranging from type 2 diabetes (Daniulaityte, 2004; Weller et al., 1999), to hot-cold concepts and classifications of food and illness (Boster and Weller, 1990; Weller, 1983), weight and obesity (Marchessault, 2001; Ulijaszek, 2007), as well as folk medical knowledge (Garro, 1986). Many of these studies have primarily taken place in Latin America (Daniulaityte, 2004; Garro, 1986; Weller, 1983) or Mexican communities in the United States (Weller et al., 1999), with the exceptions of Garro’s and Marchessault’s work among First Nation communities in Manitoba and Ulijaszek’s study in Eastern Europe. For the majority of populations and diversity of topics, cultural consensus was established with only a few exceptions. In her study on the classification of disease terms based on the hot-cold concept, Weller (1983) found little evidence to suggest the existence of a culturally shared classification system among urban and rural Guatemalan women, and was therefore able to suggest that the hot-cold concept was not viewed as a culturally significant concept compared to ideas related to contagion and severity of disease.

**Indigenous principles of research.** The research process has been positioned as an approach that emphasizes the ideal of Western science (Smith, 1999). An Indigenous researcher, Linda Tuhiwai Smith (1999) suggests developing potentially more culturally sensitive research methodologies that employ multi-disciplinary approaches. Getting the approach right is the first and major issue, and the second is employing the most appropriate methods and people (Smith, 1999). According to Smith (1999), agendas for Indigenous research constitutes the potential for action which connects local, regional and global efforts. Current *Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People* also stress that researchers need to understand and respect Aboriginal world views (CIHR, 2007). Research agendas should focus, according to Smith (1999) on a central goal of social justice which can be expressed through a wide range of psychological, social, cultural and economic terrains that simultaneously involve processes of transformation, decolonization, healing and mobilization of communities. In pursuit of such dynamic research, Smith maintains that it is critical to negotiate the processes, approaches and methodologies and be open to a wide range of influences and possibilities.

Scientific method or quantitative research is based in positivist philosophy which promotes the neutrality of the researcher, value free findings, observability and generalizability of results. As a result, the researcher must maintain maximum control over her or his “subjects” to eliminate any extraneous variables from confounding the results (Gilchrist, 1997). Perhaps the most flexible and interpretive methodology to respond to Indigenous research agendas, however, is qualitative research (Gittelsohn et al., 1996). Qualitative researchers can expect reciprocal influence to occur between

themselves and their participants through the use of open-ended processes. Another strength of qualitative research is the rich and detailed information generated to give a more elaborate portrait in answering research questions, in the case of my study, of the social and cultural context of gestational diabetes among Aboriginal women. Qualitative methods permit the use of less positivistic data collection techniques such as in-depth interviews. They are further characterised by a more equitable balance of power with minimum control on the part of the researcher; the dialogue created is compatible with the politically motivated components of decolonization and self-determination.

Participants are free to express themselves in their own terms (Sunday et al., 2001). Sampling methods and overall research design are also reflexive and permit multiple methods of data collection and analysis. Results are expressed graphically or textually and are therefore more holistic in nature and more consistent with an Indigenous worldview, or epistemology, as is further illustrated in Table 3.1, although dichotomous understandings are often limited in their explanatory power (Ermine, 1995; Gilchrist, 1997; Simpson, 2000).

The elicitation of stories or narratives through the process of open-ended interviewing is concordant with Aboriginal groups, whose stories, history and culture are based in oral tradition (Barton, 2004; Garwick and Auger, 2003; Simpson, 2000; Smith, 1999;). The talk, as Smith refers to it, about the colonial past is embedded in political discourses, music, humour, poetry and storytelling (1999). Some research methodologies exclude such extended conversation or flexible interview schedule. Mill (2000), for example, has made use of open-ended interviews which she found to be more congruent with Aboriginal story-telling in describing an explanatory model of HIV illness among

Aboriginal women. Thompson and Gifford (2000) similarly made use of an explanatory model framework as part of a larger cultural ecological theoretical orientation in devising a more culturally appropriate instrument to identify diabetes risk among Aboriginal Australians.

**Table 3.1: Comparison Between Indigenous World Views and Western Science**

<b>Knowledge</b>	<b>Indigenous World View</b>	<b>Western Science</b>
Generation	Slow/Inclusive Cyclical Spiritual includes Inexplicable	Fast/Selective Linear Theory and Laws
Communication	Oral	Literate
Transmission	Experiential Story-telling Observation	Didactic, Academic Reading, Interpreting Experimental
Characteristics	Holistic Subjective Experiential Spiritual	Reductionist Objective Positivist

(Adapted from Simpson, 2000; p.172)

Connecting more traditional patterns of thought and knowledge to modern Western ones therefore seems concordant with qualitative methodologies that utilize in-depth interviews, in the case of my study, to describe an explanatory model of gestational diabetes among Aboriginal women. Knowledge is highly rooted in practice, and traditional knowledge production requires the exchange of questions and answers (Kublu, 1999). The quality of the interaction is more important than simply ticking boxes or answering closed-format questions (Smith, 1999). As Strickland (1999) also noted in her research with Aboriginal women from the Pacific Northwest, in-depths interviews were more responsive to community needs and ultimately assisted in the design of culturally

relevant women's health education programming.

Indigenous knowledge has been described as experiential, and teaching, traditionally non-didactic (Wolfe et al., 1992). Learning therefore is often a 'hands-on' process with participation and observation. Simpson (2000) suggests this means that to experience and participate in activities relating to research is insufficient. She encourages researchers to fully participate in Aboriginal life in order to have an understanding of the culture and cautions that although there may be similarities between Indigenous worldviews, the interpretation of those similarities is dependent on the worldview of the interpreter. It is perhaps the most difficult task to negotiate between empirical and Indigenous worlds in formulating of an epistemology that is reflexive and holistic, yet sufficiently intricate to accurately conceptualize Aboriginal women's experiences. Such complex sociological and psychological conditions may not be understood by anyone who has not been born into an Indigenous way of life or Aboriginal community. In adapting and decolonizing methodologies it was therefore important to keep Smith's stated cultural ground rules in mind: respect; working with community and sharing processes, as well as knowledge (Smith, 1999).

### **Methodology**

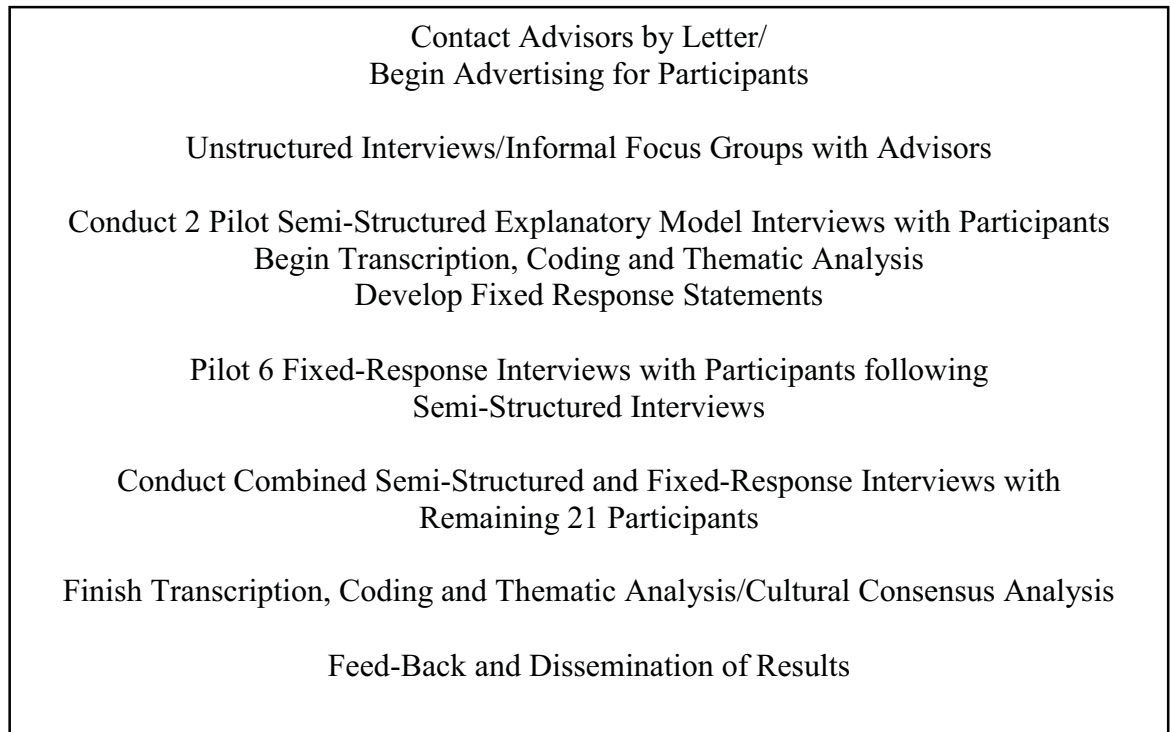
The range of interview formats utilized for this research project was intended to allow the most accurate description of the experiences of Aboriginal women diagnosed with gestational diabetes. According to Reinhartz (1992), interviewing is an effective method of describing women's experience and is consistent with an interest in avoiding control over others as well as developing a connection with people. In-depth interviewing in particular has the potential to access women's ideas and memories that are expressed

in their own words, stories and histories. It is also a reflexive method that allows for flexibility in interpretation (Reinhartz, 1992). Oakley (1981, 1993) similarly describes interviewing as a process of developing reciprocal relationships between women. Based on her own research interviewing women, she was asked to share personal information about herself during repeat interviewing. Meeting with women on more than one formalized occasion facilitated the development of relationships and allowed Oakley to establish personal involvements with her participants. She therefore became more than an instrument of data collection and introduced the concept of establishing reciprocal connections or friendships as part of the interview process. Use of in-depth interviews with Aboriginal women who have experienced gestational diabetes is consistent with and utilizes Indigenous principles of oral communication and story-telling and can be used to generate knowledge in accordance with an Aboriginal worldview, as previously described.

**Design.** To locate and design a study that incorporated methods and principles compatible with the proposed research study, a range of qualitative interview formats were chosen to provide Aboriginal women recently diagnosed with gestational diabetes the opportunity to chronicle their illness experiences. The use of explanatory model interviews and cultural consensus analysis is modeled on Garro's work (1995; 1996). Their combined application attempted to illustrate the extent to which cultural understandings are shared among this group of Aboriginal women from varied cultural backgrounds, and allow a more accurate discussion and comparison of results from the explanatory model interviews. Use of cultural consensus also assisted with data

trustworthiness to inform the overall applicability and potential transferability of study results and conclusions.

**Figure 3.1: Study Sequence**



Three separate interview protocols were conducted to achieve the research objectives. To begin with, unstructured interviews or informal focus groups took place with representative advisors<sup>1</sup> such as maternal care providers, female Elders and community leaders involved in Aboriginal women's health using questions that were formulated with the requested input from individuals working with the various organizations and institutions approached. These experienced community members provided the local context necessary to guide the semi-structured interview process.

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<sup>1</sup> Use of the term "advisor" is used throughout this chapter to replace the more common term of "key informant", which according to numerous authors can be viewed negatively (Smith, 1999; Oakley, 1981).

Second, in-depth, semi-structured interviews with Aboriginal women who had recently experienced GDM and were accessing prenatal and endocrine care within the urban centre of Winnipeg were completed. Lastly, a fixed-response interview was held with participants once several semi-structured interview sessions had taken place (see Figure 3.1 for more detail).

**Population and participant selection.** Rates of gestational diabetes are two and a half times as high in the Aboriginal population in Canada compared to the national average, with the birth rate for Aboriginal women twice that of the Canadian population overall (CDA, 2008; Health Canada, 1999). A recent publication reported First Nation women in Manitoba have a three-times greater prevalence of GDM than non-First Nation women. Higher rates of GDM were detected for First Nation women living in rural areas, most likely on-reserve (Aljohani et al., 2008a). Despite a higher prevalence of GDM among First Nation women overall, the numbers of women having experienced GDM in any one reserve community in Manitoba were believed to be too small to study as an individual group (Denise Bear, personal communication November, 2003). Although there is a lack of published literature, the number of Aboriginal women living in the city of Winnipeg who had been previously been diagnosed with GDM was thought to be sufficient to provide an adequate sample, including both First Nation and Métis women. This inference is also based on population statistics whereby 38% of Manitoba's Aboriginal women live in Winnipeg and number close to 30,000 (Statistics Canada, 2001).

Therefore a sample of Aboriginal women either living in or accessing prenatal care in the city of Winnipeg was recruited for this research project. Advertising through



posters (see Appendix A) and presentations at community health clinics and prenatal classes initially took place to raise awareness among self-declared Aboriginal women living in Winnipeg who were diagnosed with gestational diabetes either during their current pregnancy or sometime within the past five years. A total sample size of 30 women was determined to achieve maximum variation (Kuzel, 1992), saturation (Guest et al., 2006) and satisfy the requirements of cultural consensus analysis (Romney et al., 1986). Snowball sampling techniques were also necessary to achieve the proposed sample size, by requesting that participants, advisors, members of Aboriginal organizations, and personal contacts recommend names of Aboriginal women fitting the inclusion criteria who would be interested in participating. A purposive sample of 6 to 10 advisors was also selected representing urban clinics and hospitals offering prenatal services to Aboriginal women as well as Aboriginal community leaders living and working within the geographical centre of the city. An advisor or small group of advisors from each of the formalized organizations participating were asked to volunteer depending on their interest and experience.

**Instrumentation.** Initially, open-ended, unstructured interviews or informal focus groups took place with individual advisors or groups of advisors (see interview guides Appendix B). These unstructured discussions explored issues and impacts of the health care system as it exists and other external support systems or community resources influencing prenatal care services for Aboriginal women in Winnipeg with consultation provided from individuals and advisors involved with the various agencies and institutions approached. Aboriginal community leaders were similarly encouraged to discuss the availability of community and cultural support for pregnant Aboriginal

women in the city. The flexibility of unstructured interview or informal focus group formats was preferred for this first stage of the investigation because these formats are characterized as imposing the least amount of control over an individual's responses and are therefore exploratory in purpose (Schensul et al., 1999). All of the advisors were able and encouraged to express themselves in their own terms and at their own pace, as recommended by Bernard (2002).

The second series of interviews took place with the group of Aboriginal women participants. These semi-structured interviews began and ended with background questions to obtain demographic information in order to describe the sample. An interview guide (see Appendix B) was prepared to lead these interviews based on the explanatory model framework and the work of Garro (1996) and Bruyère (1998) as previously described. Interviews focused on the nature of Aboriginal women's illness experiences using a series of open-ended questions framed around six themes: causation, onset, course of the illness, treatment, pathophysiology and prevention. For this study, the theme of prevention was added as a sixth theme to explore, given a previous lack of investigation into this area. Others have proposed the framework to be sufficiently flexible to incorporate the addition of wellness themes or concepts (Arcury et al., 2004). Even though it is a more structured format than the informal interviews, semi-structured interviewing allowed the flexibility of open-ended questions. Participants were able to elaborate on their responses with additional questions or probes used as necessary (Schensul et al., 1999).

For the fixed-response interviews, a series of 36 true/false statements were created based on the results of six initial semi-structured interviews and presented in the format

of a structured interview (see Appendix B). Statements were designed to represent the reflections of women participating in the semi-structured interviews and covered topics from the explanatory model interviews. Several statements were framed around the domains of etiology, treatment, prevention, outcomes and course of illness or symptoms. Topics were selected based on their salience to women, content of the two pilots and first six semi-structured interviews. For example, statements on the pathophysiology as well as onset were not included in the structured interview even though these domains were part of the explanatory model interviews. The topics generated very little discussion.

**Implementation.** Negotiating access to Aboriginal women within the city of Winnipeg necessitated processes of consultation and collective meetings with formalized and non-formalized Aboriginal women's groups as well as maternal health care providers and community-based agencies early on in the study. As part of this process with participants and advisors, the objectives of the research were communicated clearly through initial meetings and communications with both groups, and feed-back requested to try and assure applicability and focused outcomes. As Smith (1999) asserts, the researcher needs to have thought about the larger picture of research and have a critical analysis of her own processes. The advisors, in addition to informing the research questions, were encouraged to help guide aspects of the research, especially the process of entry into the community, the content of the semi-structured interviews, and the dissemination of the study's results and recommendations.

Early on, Aboriginal women's groups and community health centres in Winnipeg were approached to seek input and support for the study. Individuals working at organizations, several local agencies, and urban health and hospital-based clinics were

asked for feedback on the research proposal and practical advice on how best to carry out the study. Willing representatives or volunteers from each of these organizations were contacted by letter (see Appendix A and Figure 3.1 for the study sequence) and asked to participate. Depending on the number of individuals that volunteered to formally participate as an advisor, either an interview or focus group was arranged, primarily at their workplace. All of these six interviews and four focus groups were audio-taped and transcribed verbatim. Field notes were also kept during this preliminary phase of the investigation and incorporated into the evolution of the interview process and study analysis.

Recruitment of participants and advisors took place from November 2006 until September 2007. Prospective participants who responded to the advertising campaign were told more about the study over the phone, and an interview time and location were arranged. Those recruited through the snowball technique had the study explained to them first by a third party before providing their contact information, or they introduced themselves after listening to an informal presentation on gestational diabetes at local community drop-in centres for pregnant women. They were usually contacted by telephone or in person if they were recruited through hospital prenatal and diabetes clinics. Women recruited by snowball sample were also given the option not to participate simply by stating their decision to their service provider, friend or other third party before any contact information was released. The majority of women preferred to be interviewed in their home. Others preferred to meet at restaurants, coffee shops, or the hospital cafeteria. In total, 30 participants were interviewed, although one woman it was

later discovered did not meet the inclusion criteria since she was diagnosed with type 2 diabetes at the age of nine.

The first two semi-structured interviews were conducted as pilots. After their transcription, revisions were made to interview questions as appropriate. These transcripts also formed the basis for writing the fixed-response statements which continued to be refined throughout the subsequent six interviews. The fixed-response interviews were then piloted twice before being administered to the remaining 21 participants directly following their semi-structured interview. Each statement was read to the participants, following the explanatory model interview, to avoid influencing responses (Garro, 1996). Upon listening to each statement, participants were asked in their opinion whether the statement is true or false. Additional comments were also recorded and incorporated into the overall analysis that included pilot responses to the statements.

**Analysis.** The overall analysis for this study was based primarily on Garro's research on the topic of type 2 diabetes among Aboriginal communities (1988 and 1996), using both open-ended semi-structured interviews and consensus analysis to determine the extent to which cultural understandings are shared among participants. Open-ended responses to the EM interviews were explored to suggest patterns in these shared understandings, forming the basis for the consensus statements. Participants' discussions arising from the semi-structured EM interviews were also analyzed individually to provide broader context for interpreting the results.

During the collection period, all of these interviews and focus groups were audio-recorded with permission and transcribed verbatim as soon as possible afterwards. Both

the unstructured and semi-structured interview transcriptions were then read and re-read for descriptive themes, accuracy and content. Categories and themes that emerged from the transcripts and field notes were then organized and coded using NVivo7 (Qualitative Solutions and Research, 2006). The software was also used to browse, search and interpret the interview text through the creation of models and memos (Richards, 2005). Thematic analysis was then employed along with coding and matrix queries to assist in further identifying relationships between categories according to participant attributes (Bazeley, 2007).

Cultural consensus analysis was subsequently used to analyze the dichotomous responses arising from the fixed-response interviews (Romney et al., 1986). Using ANTHROPAC 4.0 (Borgatti, 1994), nominal data were used to explore agreement and variation among the group of Aboriginal women. There were two stages to the consensus analysis. Agreement and disagreement regarding content of consensus statements were explored first, and then patterns of response in the second stage. The assessment of whether or not the set of statements drew upon a shared cultural domain was derived from a factor analysis of the matrix of responses among the women responding. The process of analysis begins by calculating a matrix of response matches among participants. The matrix is then corrected for guessing and factor analyzed, with the first factor representing “cultural competence” or sharing. Each of the subsequent factors account for the remaining variability, but if the assumption of a shared cultural domain is met, the first factor will account for the matrix structure. Therefore, the amount of variance represented by the first factor should be several times larger than the second factor, with all others being smaller and positive (Romney et al., 1986). To support the

assumption of shared cultural understanding, the amount of variance associated with the first factor must be at least three times as large as the second factor with all other factors relatively small and positive (Weller and Romney, 1988). The first factor represents “cultural competence” and will account for the structure of the matrix if the assumption of a shared cultural domain is met (Kempton et al., 1995). Otherwise, a common culture cannot be assumed, and it would not be meaningful to aggregate responses.

Following consensus analysis, participants’ responses were further examined to determine additional patterns of variation based on personal attributes such as age, parity and location using the quadratic assignment program (QAP) from the Anthropac 4.0 analysis package (Borgatti, 1994). QAP tests for differences between groups by testing the similarity of two proximity matrices, one containing observed data compiled by the structured interviews used to test cultural consensus, and the other a structure matrix of expected responses. QAP correlates these two matrices cell-by-cell, then compares this observed correlation to a distribution of correlations generated by correlating hundreds of randomly permuted matrices. A significant result for the QAP indicates that the observed similarity between matrices is unlikely to have occurred by chance (Borgatti, 1994). Therefore QAP tests for differences between groups by comparing matrices and has been used by others as part of cultural consensus analysis (Garro, 1996; Marchessault, 2001). Overall, these analyses suggested possible conclusions regarding similarity and dissimilarity of cultural understandings within the sample of Aboriginal women. These results are featured in Chapter Four.

**Ethical considerations.** Formal consent was negotiated with both advisors and participants at the beginning of each interview (see consent forms in Appendix D). A

written consent form was presented to each individual and the study's objectives were explained in detail. It was also stressed that participation was voluntary and individuals may refuse to answer any question or decide to discontinue their association with the study at any time. Protocols to protect confidentiality of all participants and advisors, as well as my intention to include Aboriginal women and community advisors in the research process and dissemination of the results were discussed and will be adhered to in accordance with *The CIHR Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007). In addition, anonymous quotations will be used in any report or publication resulting from the study and any details in the quotations will be altered if necessary to protect the participants' identities. Publications and presentations will recognize the contribution of all those who participated. Participants and advisors were also encouraged to participate in the dissemination of the overall results.

All of the interviews and focus groups were conducted only once informed consent had been established with both advisors and participants. Prior to data collection, ethical approval for the study was received from the University of Manitoba Health Research Ethics Board, the Health Sciences Centre Research Impact Committee, Health Canada Research Ethics Board, and the Winnipeg Regional Health Authority Research Review Committee (Appendix C).

### **Limitations and Implications**

As is true of most research, there are limitations imposed by methodologies, theories and the researchers themselves. The desire to use a variant of an Indigenous research framework, for example, was difficult to combine with the rigidity of cultural consensus theory in this study. Attempting to incorporate components of Smith's (1999)



Indigenous research agenda ultimately requires the adaptation of philosophies centered around much larger issues than a study of this scope and topic can adequately approach as a student-led research project. I feel strongly, however, that it is important to acknowledge and develop alternative methodologies with the hope that future research projects and processes involving Aboriginal groups can build upon these frameworks and adapt them to their unique frame of reference.

Cultural consensus theory has been perceived as somewhat reductionist. As Strickland (1999) and Simpson (2000) have noted, circular models are more representative of an Indigenous world view rather than linear or mathematical paradigms. In addition, the use of the word culture can be perceived as problematic depending on its definition (Gray and Thomas, 2006). In anthropology, culture has been described as being what people have to learn that is distinct from their biological heritage (Goodenough, 1964). Culture must therefore consist of the knowledge people use to live their lives and the way in which they do so (Romney et al., 1986). Handwerker (2002) has acknowledged, however, that historically assumptions, not evidence, were used to equate culture with social identities. Cultural variability among individuals and groups was frequently overlooked. Discordance between individuals, groups, cultures and their social identities appears to fit more closely with the idea that culture is not bounded (Keesing, 1994). Cultural consensus analysis combined with the quadratic assignment program may provide however, in this case, a more objective way of understanding individual's perspectives by challenging researchers to look for differences as well as similarities among participants.

The more rigid interview format associated with cultural consensus theory is

certainly not as subjective or flexible as the in-depth interviews associated with EMs. Consensus theory has also been criticized for its unrealistic assumptions and its potential to perpetuate assumptions among essentialized social groups (Handwerker, 2002). Open-ended interviews are more congruent with Aboriginal oral traditions such as story-telling as a method of transferring information (Mill, 2000). From a more empirical perspective, however, Garro (1996) has recommended the use of these two kinds of data because open-ended responses on their own are difficult to compare. Purely qualitatively based research tends to assume cultural homogeneity and behavioural sharing. The issue of intra-cultural variation is rarely addressed and is therefore not able to make a systematic connection between the cultural, social and individual aspects of human behaviour (Daniulaityte, 2004).

As previously described, the use of cultural consensus does permit a smaller sample size; however, because the participants who participated in this study constituted a volunteer and non-randomized sample, the study's results will not be directly transferrable. Only one primary investigator was involved in the collection and analysis of the interviews, a limitation which may narrow the interpretation of the thematic analysis and hence credibility of the results. In addition, the lack of a formal participatory framework or research design which would more fully include participants and advisors in the research itself could be viewed as a limitation. Participation and action as formalized methods, however, raise many issues that would need to be addressed for the research to proceed and be completed within the time-frames and other externally imposed guidelines as a graduate student.

Is it possible to create and conduct research in an academic context that is

compatible with Indigenous worldviews? The location of this study along any kind of gradient is linear and therefore immediately indicative of a Western scientific schema. From the same vantage point, the methods utilized have limitations that similarly align themselves with Western scientific thought. The use of explanatory model frameworks, for instance, although incorporating in-depth interviews which are more flexible in their approach, have been criticized for failing to address the social, economic and political causes of illness or their influence on personal illness experiences (Singer, 1995). Meeto and Meeto (2005) also caution that divergent cultural backgrounds of researcher and participant could hinder disclosure and thereby threaten the relevance or accuracy of the interviews. Arcury and colleagues (2004) used Kleinman's methodology to investigate diabetes meanings among those without diabetes and questioned the compatibility of EMs with wellness and diabetes prevention. All of these concerns bring into question the narrow focus of explanatory models in practice and whether or not they are completely holistic in their application or congruent with Indigenous principles of generating knowledge.

Incorporating Indigenous principles into formalized research methods may also give rise to theoretical issues, such as the flexibility of the methods in application compared to 'scientific rigour' necessary to implement them and report on their results from within an academic institution. The triangulation of results from the three separate interview formats was used to inform the overall applicability and transferability of the results and study conclusions. However, even if the study's findings are deemed 'valid' or transferable according to scientific standards, the benefits of the research for its participants are of utmost importance (CIHR, 2007). Western scientific concepts and

research methods that have been developed outside Aboriginal communities may also be of little relevance from an Aboriginal community's perspective (Smylie et al., 2004). These are also ethical issues; it must be determined who is to benefit from the study and who may be harmed or further disenfranchised (Miles and Huberman, 1994). As Khanlou and Peter (2005) have also stated, "a research project must use rigorous scientific principles and methods to be ethical." An inability to produce meaningful results could be a waste of resources and time and thereby be potentially exploitive to participants (p. 2336).

Ethical implications are among the most numerous and challenging determinations in preparing to conduct research that is both scientifically sound and relevant to Aboriginal women. Issues of informed consent, confidentiality, ownership, location of 'power', and benefits to the participants have arisen from several projects involving Aboriginal and non-Aboriginal communities (Abonyi, 2001; Dickson, 2000; Garwick and Auger, 2003; Hiebert, 2004; Lofman et al., 2004). Any participation in women's lives outside of a structured, purely academic research context could be similarly ethically problematic. The development of relationships, community activism, participation and functioning in programming may be perceived as moving beyond the bounds of the primarily compartmentalized researcher-community partnerships. Piquemal (2001) as well as Smith (1999) have also stressed that concepts of power and former colonial domination are areas that need to be carefully addressed in negotiating access as well as consent, as was previously described. Consent should be continually informed by consulting with participants in an ongoing process of renegotiation (Piquemal, 2001). Smylie (2005) similarly cautions that consultations should take place with Aboriginal

community members in the development of the research, the interpretation of the data and dissemination of the results. These procedures are also included in the *CIHR Guidelines for Health Research Involving Aboriginal People* (2007), as described previously.

The ethical, theoretical and methodological orientations of this study attempted to focus on the personal as well as the culturally-mediated meanings of health and illness. A comprehensive and holistic approach towards an ideologically grounded understanding of Aboriginal women's perspectives on gestational diabetes needs to incorporate the experience as lived. To explore the nature of Aboriginal women's illness experiences and how they interface with socio-cultural, historical and political systems, the full range of human experience needs to be incorporated. In this context, Indigenous ways of creating and transmitting knowledge were negotiated in an effort to provide the most accurate and balanced recognition of Aboriginal women's understandings of gestational diabetes mellitus in an urban setting.

## **Chapter Four**

### **Aboriginal Women's Understandings of Gestational Diabetes within the Urban Context of Winnipeg, Manitoba: An Exploration Using Cultural Consensus Analysis**

An estimated 150 million people worldwide were diagnosed with diabetes in the year 2000. By 2025 this figure is predicted to increase to 380 million (CDA, 2008). For Aboriginal<sup>1</sup> groups type 2 diabetes is of particular concern and widely considered to have reached epidemic proportions (Dyck et al., 2010; King et al., 1998; Young et al., 2000). Rates of gestational diabetes mellitus (GDM) are also considerably higher among Aboriginal women. Reported prevalence rates for GDM range from 11.5 to 14.9% among Oji-Cree and James Bay Cree women compared to about 3.7 percent of Canadian women. Most women develop GDM during their second trimester of pregnancy (Brennand et al., 2005; CDA, 2008; Dyck et al., 2002; Godwin et al., 1999; Harris et al., 1997; Rodrigues et al., 1999a). Investigators also caution that like type 2 diabetes, GDM appears to be on the increase across population groups with Australian researchers reporting a recent 45% increase between 1995 and 2005 among the general population of women in New South Wales (Vibeke et al., 2008). In Manitoba, the overall prevalence of GDM has risen to 3.7% in the last decade with rates among Aboriginal women three times greater than the general population (Aljohani et al., 2008a).

Insufficient literature currently exists, however, on the topic of GDM in Aboriginal populations. Few investigators have examined how women experience and understand gestational diabetes. There are remarkably few published descriptions of programs that

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1. In Canada, "Aboriginal" includes status and non-status First Nation, Inuit and Métis people (Frideres and Gadacz, 2001) and will be used throughout this paper to refer to the women of self-declared First Nation and Métis backgrounds who participated in this study.

focus on the prevention of gestational diabetes and healthy lifestyle promotion among Aboriginal women and children. There has been a lack of evidence that these interventions result in lowered diabetes incidence in the communities targeted (Dyck et al., 1998; Gray-Donald et al., 2000; Paradis et al., 2005). In addition, qualitative investigators have rarely explored how women experience gestational diabetes with all of the lifestyle behavioural change its treatment and prevention require. For Aboriginal women living in urban areas who appear to be at greatest risk of developing type 2 diabetes, there is an even larger gap in the published literature (Feig et al., 2008; Vibeke et al., 2008). Only a handful of qualitative studies have taken place with non-Aboriginal groups in Canada, the U.S. and Europe (Evans and O'Brien, 2005; Hjelm et al., 2005; Hjelm et al., 2006; Kieffer et al., 2002; Lawson and Rajaram, 1994). Smith-Morris (2005, 2006) has done the most extensive work with pregnant Pima women on the Gila River reservation in Arizona. Focusing on women's experiences and interpretations of GDM, she suggests, is important for greater understanding of health seeking patterns and behaviours.

The current study is an in-depth qualitative investigation with Aboriginal women from a variety of backgrounds accessing prenatal care in an urban context, with the primary objective to describe Aboriginal women's understandings of GDM based on their own explanations of the illness. In this study, I sought to explore how Aboriginal women understand the onset, causes, course, pathophysiology, treatment, and prevention of their condition, while attempting to discern to what extent these cultural understandings are shared among a diverse population of Aboriginal women in Winnipeg, Manitoba.

## **Methodology**

Because very little research has been undertaken on this topic, qualitative methodology was selected. Qualitative methods are chosen when a detailed understanding of a process or experience is needed or when further information is required to determine the exact nature of the issue being investigated. Interpreting the unstructured or semi-structured data that arises from the interviewing process also allows greater exploration, description, comparison, pattern analysis and theory testing (Bazeley, 2007). The primary method of data collection used was interviewing. The study was part of a larger research project that included unstructured interviews and informal focus groups with representative advisors<sup>2</sup> such as maternal care providers and community leaders involved in Aboriginal women's health to inform and guide the research. These results are presented elsewhere (Chapter 5). Semi-structured EM interviews were subsequently conducted with women who self-identified as Aboriginal and either currently had GDM or had been diagnosed with it within the past five years. For the majority of participants, these interviews ended with a fixed response interview in order to assess cultural consensus among the sample of Aboriginal women. The overall method for this study is based on Garro's research on the topic of type 2 diabetes among Aboriginal communities in Manitoba (1988; 1995; 1996).

**Explanatory model framework.** According to Kleinman (1980), illness is culturally shaped. Explanatory model frameworks are subjectively and personally constructed, thereby reflecting the culturally situated meanings of an illness or condition such as gestational diabetes and incorporate the psychological and cultural aspects of the

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<sup>2</sup> Use of the term "advisor" is used throughout this paper to replace the more common term of "key informant", which according to numerous authors can be viewed negatively (Smith, 1999; Oakley, 1981).



illness from the patient's perspective (Kleinman et al., 1978; Meeto and Meeto, 2005) and other salient factors such as societal influences, history and gender that also impact upon an individual's illness experience. According to Kleinman (1980), these frameworks are viewed as the cognitive belief structures created to recognize and respond to a specific illness experience, therefore potentially assisting with an individual's ways of coping and making sense of their state of being.

Explanatory models (EM) generally contain explanations of five issues or themes: onset; etiology; course of illness; pathophysiology, and treatment (Kleinman, 1978). Open-ended questions around these issues are developed and used to guide semi-structured interviews. The wording of the questions can vary depending on the participants' characteristics, their illness and the interview setting (Kleinman, 1980). For this study, the theme of prevention was added as a sixth theme to explore. Others have proposed the framework to be sufficiently flexible to incorporate the addition of wellness themes or concepts (Arcury et al., 2004). The methodology has been mainly used by medical anthropologists to work towards a better understanding of health practices and behaviours in a number of cultural settings including several Indigenous or Aboriginal groups (Arcury et al., 2004; Bruyère, 1998 and 2006; Bruyère and Garro, 2000; Garro, 1988 and 1995; Jezewski and Poss, 2002; Lang et al., 2004; Meeto and Meeto, 2005; Mill, 2000; Poss and Jezewski, 2002; Sunday et al., 2001; Thompson and Gifford, 2000). A wide range of illnesses have been examined through these investigations. The illness experience of type 2 diabetes, for example, has been studied among Canadian (Bruyère, 1998 and 2006; Bruyère and Garro, 2000; Garro, 1995; Sunday et al., 2001) and Australian (Thompson and Gifford, 2000) Aboriginal groups, as well as in Asian,

Caucasian (Meetoo and Meetoo, 2005) and Latino or Mexican communities (Arcury et al., 2004; Jezewski and Poss, 2002; Poss and Jezewski, 2002).

**Cultural consensus theory and analysis.** Cultural consensus theory provides a way to ascertain whether or not shared understandings exist within a group or community (Romney et al., 1987). It is based on the conceptions that, people share perceptions of the world, and patterns of agreement and disagreement in these understandings can be measured (Weller and Romney, 1988). If shared understandings are determined, the theory permits comparisons between participants to more accurately evaluate the degree of concurrence or convergence of response (Garro, 1996). The central idea of the theory is therefore that patterns of agreement or consensus among participants may be utilized to make inferences about their knowledge of the answers to the questions posed (Weller and Romney, 1988). Cultural consensus allows this “cultural knowledge” to be measured and its distribution among respondents described mathematically, provided the three assumptions underlying the model are met (Romney et al., 1986). They include: 1) there exists a single culturally acceptable answer for each question, which if known, is consistently given; 2) each question is answered independently and respondents answer independently of each other; and 3) all of the questions are drawn from the same cultural domain (Borgatti, 1994).

The technique of cultural consensus analysis developed by Romney, Weller and Batchelder (1986) measures patterns of agreement and disagreement within a cultural domain, or estimates how much each participant “knows” on a given topic. Assuming that the correspondence between any two individuals is a function of the extent to which each has knowledge of the most commonly given answers, more “knowledgeable”

participants are expected to give a higher proportion of “correct” answers, and consequently respond more similarly to each other compared to those with less “knowledge” about the domain of study (Weller and Romney, 1988). Consensus analysis estimates these patterns of agreement and disagreement by weighting each of the participant’s responses and uses the aggregate to predict the most likely answers, or approximates the reliability of the information content of an interview (Weller and Romney, 1988).

The process of analysis begins by calculating a matrix of response matches among participants. The matrix is then corrected for guessing and factor analyzed, with the first factor representing cultural consensus. Each of the subsequent factors account for the remaining variability, but if the assumption of a shared cultural domain is met, the first factor will account for the matrix structure. Therefore, the amount of variance represented by the first factor should be several times larger than the second factor, with all others being smaller and positive (Romney et al., 1986). A common culture cannot be assumed if these conditions are not met and it would therefore not be meaningful to aggregate responses.

When interviewing to explore cultural patterns for a specific topic or domain, or attempting to determine the potential for high agreement within a domain, cultural consensus analysis allows reliable answers to be obtained even with a small number of participants (Weller and Romney, 1988). The reliability for a set of responses is derived from the number of respondents and the extent of agreement between them (Weller and Romney, 1988). For example, few lacrosse players would be necessary to give reliable and accurate information about the rules of the game compared to a large random sample

of musicians if posed the same questions. Therefore only a small number of participants is necessary to reliably predict culturally congruent responses, since cultural consensus theory is used to predict cultural knowledge of a domain with a single answer for each question that has been ethnographically informed (Romney et al., 1986). Cultural consensus analysis is therefore not meaningful on its own (Garro, 1988). Open-ended questions designed to elicit explanations are required to determine the content of the structured interview statements and to understand the overall results.

Authors such as Garro (1988a, 1995 and 1996), Daniulaityte (2004), Moore (1997) Weller and colleagues (1983 and 1999), among others have used cultural consensus analysis in combination with qualitative interviews to help clarify the consensus analysis and thereby estimate the degree to which each participant represents shared cultural knowledge on a given topic or domain (Garro, 1995). Garro, for example, has used both explanatory model interviews and cultural consensus analysis to compare causal accounts of type 2 diabetes mellitus in a Manitoba *Anishinaabe* (Ojibwe) community. Using two kinds of data she was able to establish agreement and variation within the community, and establish two main cultural models to incorporate individual's complex understandings of diabetes etiology (Garro, 1995).

**Implementation.** A sample of 30 self-declared Aboriginal women who had been diagnosed with gestational diabetes during their current pregnancy or within the past five years was recruited for this research project. Potential participants responded to posters displayed in various health care and community locations throughout Winnipeg. The author made informal presentations on the topic of GDM to various community and prenatal women's groups to create awareness and establish contact. In addition, the

author also attended weekly antenatal and diabetes education clinics where women fitting the criteria were privately told about the study by nursing staff and asked if they wished to participate in the study. If they were interested, potential participants were then introduced to the author who explained more about the study and set up a mutually agreed upon time and location to conduct the interview.

The semi-structured explanatory model (EM) interviews began and ended with background questions to obtain demographic information. The central part of the interviews focused on the nature of Aboriginal women's illness experiences using a series of open-ended questions framed around the six themes as described previously (Kleinman, 1978). Sample questions can be found in Table 4.1. The first two EM interviews were conducted as pilots to test the interview format, sequence and content of questions. After interviews with six women, a series of true and false statements were created for the fixed-response interviews. Statements were designed to represent the reflections of women participating in the semi-structured interviews, and covered the topics that were most common such as the etiology of GDM, course of illness including symptoms and outcomes, as well as treatment and prevention. These fixed-response statements were piloted with two more participants before becoming finalized. The resulting interview guide of 36 statements was used with the remaining 21 women directly following the semi-structured interview questions. Each statement was read to the participants directly following the explanatory model interview to avoid influencing responses to the open-ended questions (Garro, 1996).

Ethical approval for the study was received prior to data collection from the University of Manitoba Health Research Ethics Board, the Health Sciences Centre

Research Impact Committee, Health Canada Research Ethics Board, and the Winnipeg Regional Health Authority Research Review Committee. Interviews were conducted by the author once informed consent had been established.

**Analysis.** All interviews were audio-recorded and transcribed verbatim. Field notes were also kept during the process of data collection. All of these documents were imported as text files into NVivo7 (Qualitative Solutions and Research, 2006). Using NVivo, transcripts were read, searched and coded into categories and eventually themes using a method of constant comparison (Lincoln and Guba, 1985). The process of analysis also involved connecting ideas and establishing relationships through modeling and writing memos to add to an analysis sequence, supporting the rationale and sequential process of the findings (Richards, 2005). Themes and categories were then further analyzed through matrix coding inquiries that permitted the comparison of emergent themes with participant characteristics or attributes (Bazeley, 2007). This cross-comparison of participants based on their demographic profile compared to thematic concepts coded into node categories provided a more complete description of participants' experiences. Through this process the complexity of each individual's attributes and responses are retained as they are compared in a search for common patterns and emerging theories (Bazeley, 2007).

Although the group of Aboriginal women accessing prenatal care in the city of Winnipeg do not constitute a formalized group or community, cultural consensus analysis was useful to determine whether or not aggregate responses collected from the participants may be directly compared. Cultural consensus analysis was used to analyze the dichotomous responses arising from the fixed-response interviews (Romney et al.,

1986). This nominal data was used to explore agreement and variation among the participants, using Anthropac 4.0 (Borgatti, 1994). Following consensus analysis, participants' responses were further examined to determine additional patterns of variation based on personal attributes such as age, parity and location using the quadratic assignment program (QAP) from the Anthropac 4.0 analysis package (Borgatti, 1994). QAP tests for differences between groups by testing the similarity of two proximity matrices, one containing observed data compiled by the structured interviews used to test cultural consensus, and the other a model or structure matrix of expected results. A proximity matrix was created of inter-participant correlations based on each of the three variables to be tested. This matrix was then compared to a structure matrix representing expected agreement to the model (for example, see Figure 4.1 constructed for parity). The number 1 was placed where agreement is expected. QAP then determined how well the structure matrix fits the proximity matrix by creating comparison distributions generated through a random permutation process, which can be interpreted like a  $p$  value (Borgatti, 1994; Garro, 1996). According to other analyses using QAP, the level for rejecting the null hypothesis has been set at  $p < .05$  and is appropriate given the exploratory nature of the study (Garro, 1996; Marchessault, 2001). A significant result for the QAP indicates that the observed similarity between matrices is unlikely to have occurred by chance (Borgatti, 1994). Binomial testing was also performed for each of the 36 statements using SPSS. Overall, these analyses allow conclusions regarding similarity and dissimilarity of cultural understandings within the sample of Aboriginal women, with the results featured in relation to the explanatory model interview content.

**Research Setting.** Winnipeg is a geographically isolated city of 633, 450 people (Statistics Canada, 2006). It is the capital of the province of Manitoba and situated close to the longitudinal centre of Canada. According to the 2006 Census, the metropolitan area of Winnipeg has the highest number of Aboriginal people in Canada with 68,380 reporting Aboriginal ancestry. This represents 10% of Winnipeg's population. Many Aboriginal families in Winnipeg live in temporary or sub-standard housing in areas of the city where housing is less cost-prohibitive, since close to 65% of Aboriginal households in Winnipeg are below the low income cut-off (LICO) (Kaufman et al., 2000). Most families live close to the city centre or the "inner city" as it is commonly referred to. Within these geographical districts they account for more than 20% of the population (Government of Manitoba, 2000). This core area of Winnipeg can also be unsafe for its residents with hospitalization rates for violence 6.6 times higher (Government of Manitoba, 2000). In all Winnipeg neighbourhoods Aboriginal families tend to be more transient and have unemployment rates significantly above average (Government of Manitoba, 2000). Aboriginal women who have grown up or currently live in the inner city, including the northend of Winnipeg comprise 86% of the sample of Aboriginal women participating in this study.

## **Results**

**Participant description.** Recruitment of a volunteer sample of 30 participants took place from November 2006 until September 2007. Each of the participants was usually interviewed once, with the interview lasting an average of one hour and nine minutes. Women ranged in age from 18 to 43 years of age (median 30). On average they had three children (range 0-10) and 16 were pregnant at the time of the interview. Nine



women had GDM at the time of their interview, 11 had experienced it previously and reported normal blood glucose readings while participating in the study. At least nine participants had been diagnosed with type 2 diabetes, after their GDM diagnosis although not everyone had been tested postnatally. More than 60% of the women's own mothers had been diagnosed with type 2 diabetes. While receiving treatment for GDM, 18 of the 29, or 62% of participants were prescribed insulin to manage their blood glucose (BG) levels. Pseudonyms and additional details on diabetes and prenatal status for participants are included in Table 4.2.

Over 30% of participants grew up in Winnipeg. One woman from a northern reserve community was, however, excluded from analysis because it was later determined she had been diagnosed with type 2 diabetes when she was nine years old, and therefore did not meet the sampling criteria. This brought the sample size of participants to 29. Four of these participants were living on-reserve at the time of the interview, but travelled to Winnipeg for healthcare. Fifteen women had moved to Winnipeg as adults to work or attend school. Twelve women self-identified as Saulteaux or Ojibwe women, nine as Cree, two as Oji-Cree and four as Métis. Two others were unsure of their Aboriginal backgrounds since they had grown up in foster care. For further demographic description see Table 4.3.

**Interpretation of cultural consensus.** Cultural consensus analysis was run for the 36 statements framed around the central domain of gestational diabetes and separately for the smaller domains or topics that included: etiology, course or symptoms, treatment, outcomes and prevention. As can be seen in Table 4.4, for the entire set of statements the eigenvalue ratio is 4.12, which is consistent with other studies in support of the

assumption of shared understandings (Garro, 1988 and 1996; Marchessault, 2001; Daniulaityte, 2004). The mean values for the consensus factor, represent a numerical estimate of the degree that each participant shares cultural knowledge for a specific domain. The overall mean for the entire set of 36 statements on gestational diabetes is .48 and can be further interpreted to illustrate that 74% of the true-false responses reflect shared cultural knowledge on this topic.<sup>3</sup> None of the individual factor loadings were less than zero and 74% of the values were 0.50 or above (data not shown). This percentage, however, is lower than others have reported among Manitoba Aboriginal communities which were 80% and higher (Garro, 1986; Marchessault, 2001). Therefore, although the ratio of the first to second eigenvalues was sufficiently high at 4.12 to indicate consensus was achieved, the average extent of agreement for this group of Aboriginal women was low.

To assist in further determining patterns of responses for the 21 women, consensus analysis was also carried out for the five sub-topics. None of the first to second eigenvalue ratios listed in Table 4.4 were higher than three. Mean consensus factors were low, particularly for the domains of etiology, course of illness and outcomes. The output of factors loadings for each sub-topic also contained at least one negative factor, with etiology and outcomes including six and five, respectively (data not shown). Therefore, for these separate topic areas, it was concluded that cultural consensus could not be established. There was not enough evidence to support the assumption of shared understandings in these areas, however, there may not have been sufficient power from these smaller data sets to draw any significant conclusions (Weller and Romney, 1988).

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<sup>3</sup> This estimate is obtained by adding to the overall mean half of the remaining questions individuals can be expected, on average, to guess in unison with the culturally shared response  $(0.48 + (1 - 0.48) / 2 = 0.74)$

**Shared understandings.** To further interpret and analyze the results of the responses to the fixed response statements for the group of participants as a whole, binomial tests were performed for each using SPSS with a confidence level set at  $p < 0.01$ .<sup>4</sup> Table 4.5 lists the 13 statements that attained this level of significance, including another five that met  $p < 0.05$ . The table also includes the proportion of participants who either agreed or disagreed with the statements, along with the explanatory model category represented.

**Onset.** At the beginning of the explanatory model interviews, participants were asked to describe their thoughts when first diagnosed with GDM. Although the topic of onset was not included in the consensus statements because of a lack of discussion generated from the initial EM interviews, much of what the group of women initially understood about GDM was based on preliminary encounters with health care professionals. Few participants had extensive personal knowledge based on more informal discussions, even though family members had also experienced GDM. Amber talked frequently about her initial fear when she was first diagnosed with GDM. As she described her reaction: *“it kind of was upsetting ‘cause I didn’t know what to expect. ‘Cause you don’t hear a lot about it. And ‘cause my mother had it with me I asked her about it and she didn’t know, either. We weren’t taught anything about it.”* Women’s reactions were not always the same, however. Not everyone expressed worry or surprise when diagnosed. Trisha’s mother also had GDM when pregnant with her. She said, *“most of her family”* in her reserve community had diabetes and explained her response to a diagnosis with GDM as, *“I wasn’t surprised that I had it because I knew my Mom had it.”*

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4 Even though the consensus program provides an “answer” for each response or question, to be considered a consensus response this set criterion must be met (Garro, 1996).

**Treatment.** Ideas most commonly shared from the cultural consensus analysis are, however framed around concepts associated with mainly biomedical explanations for GDM. These results correspond to the overall consensus analysis that revealed a higher level of congruence within the topics of treatment as well as prevention (Table 4.4). The first two statements in Table 4.5, for example, achieved the highest proportion of agreement which seems to reflect women's exposure to diabetes education messages relayed from health care providers. Participants would frequently communicate treatment messages during the explanatory model interviews. When asked what some of the most important things she learned having had GDM, Nancy responded, "*watch my weight gain, [not] eating too many sweets, keep myself hydrated and kind of do little exercises, don't lie down too much. Those were the big main things.*" Alice similarly recited the messages she was most familiar with: "*eat well, exercise, and just follow the doctor's orders, you know? If he tells you to eat well you still can, just avoid the sugars and fat.*"

**Etiology.** Even though consensus was not established for the domain of etiology, statements three, five and six achieved high levels of agreement according to the binomial criterion, as indicated in Table 5. It is interesting to note that these statements also reflect formalized health care messages associated with GDM. Being overweight, heredity, dietary and activity patterns were strongly linked with the development of GDM, according to the group of participants responding to the yes/no statements. These concepts were also discussed frequently during the qualitative interviews, although there was often significant overlap between comments on treatment, causation, and prevention. Alice and Claire provide good illustrations. Alice began a discussion of GDM causation, stating emphatically, "*personally, I think the genetics is just a load of crap,*" and went on

to say, *“I think it’s just another excuse for diabetes or gestational because I think each individual gives it to itself because of the way they eat. I used to think it was genetic. Sometimes I still do.”* Claire similarly constructed her own opinion on the increasing number of women in her community who were developing GDM. She based her interpretation on conversations she had had with Elders who talked about the dramatic changes they had witnessed during their lifetime. She explained, *“that’s one of the reasons why some people say back home. Nowadays, the people our age aren’t eating our Native foods.”* However, when she was asked if she was encouraged by her family or community to eat more of these wild foods when she was pregnant she responded, *“no, they just encourage us to eat healthier and to exercise.”*

**Prevention.** The semi-structured interviews discussions on the topic of prevention seemed to be based on interactions participants had had with biomedical practitioners. Carole and others again referred to the concept of individual responsibility when discussing options for preventing gestational diabetes among Aboriginal women. Carole suggested, *“I think they should be more active. There’s a lot of them that live in this city and there’s lots of places where they can be active. They could get their kids active, instead of sitting at home in front of a satellite 24/7 doing nothing but eating.”* Amber also definitively stated that in terms of prevention, *“I think it’s all on us. I think we have to exercise more and eat healthy. I think that’s all it is.”* A significant proportion of participants, however, felt there was not enough awareness about GDM to focus prevention efforts, as indicated by the statements 4 and 18 listed in Table 4.5. As Amber also stated, *“there needs to be more awareness about what to do to prevent it.”* This lack of awareness may help to explain the variation in interpretation of the concept of

prevention as it relates to personal control over GDM. Both Lori and Diane had prior pregnancies with GDM and tried to prevent it from developing again with their most recent babies, but were frustrated that following the advice they had received on lifestyle changes was not effective. Lori said when she was diagnosed again she thought, *“I didn’t believe I have it because I’m watching what I eat. I’m exercising and doing all the right things that I hadn’t done in my first pregnancy.”* Diane was similarly discouraged: *“I tried hard to prevent it this time, but I still got it. I drank water. I started eating diabetic right away, but I still got it.”* This lack of personal control over the onset and diagnosis of GDM was not shared by everyone. Doris was thankful she had become more aware of her eating patterns during her pregnancy and found the experience, *“made me get it under control, and it was great to know that you could take control and do exercise and healthy eating.”*

**Personal deviations of GDM experience.** Although there are several other statements that nearly reached statistical significance, Table 4.6 lists the remaining 18 that produced a much more variable response. Topics that showed the least proportion of agreement, appeared to reflect personal experience and individual interpretation of risk. There was marked disagreement for instance in the areas of illness course in terms of both symptoms and outcomes. Several statements listed in Table 4.6 related to symptoms or reactions women may or may not have experienced with GDM, such as feeling emotional fluctuations resulting from high blood glucose levels. Statements producing the least amount of consensus for both agreement and disagreement were on the topic of course of illness including symptoms (35) and verging on the area of pathophysiology (36).

**Pathophysiology.** Concepts associated with the pathophysiology of GDM were generally complicated and confusing for most of the participants. There were only three women who answered the EM questions on this topic with assurance. Not enough discussion was generated on this topic to include it as part of the consensus statements. This confusion was reflected in women's responses. During the semi-structured interviews it was clear that these ideas were perplexing to women. When Deb was asked if she felt she understood why she developed diabetes during pregnancy she responded, "*I didn't know what it was, and then when she told me that I got it, I was catching bits and parts and it was the insulin that was needed in your body that something in your body wasn't giving out. [The dietitian] may have mentioned and said more, but it just didn't compute.*" Sandy was similarly confused about the pathophysiology of GDM, but seemed to determine for herself that even if other women may think they don't have diabetes, she explained as best she could translate from Oji-Cree into English, "*sometimes diabetes might be hidden in your blood.*"

**Course and symptoms.** How gestational diabetes is physically interpreted and the level of control women feel over their bodies and symptoms are closely tied together. Carole described it like this: "*it just sneaks up on you whenever it wants. Just come and go whenever it pleases or it could just stay if it wants. It's not up to us when we're going to get it, how we're going to get it and what's going to happen to us when we have it. It's all up to our body.*" These sentiments are indicative of the perspective provided by statement 31 in Table 4.6, which reflects a lack of bodily control. Carole found GDM to be constraining on her body stemming from a lack of control: "*when I'm not pregnant, I could move around a lot more. But being pregnant with it, it's hard to control it because*

*the baby's also bringing the sugar on me. So when you're not pregnant and you're diabetic, you could easily control it yourself because you don't have to worry about feeding anybody else but yourself."*

The worry and anxiety about having diabetes while pregnant, was echoed by several more participants during the explanatory model interviews, however participants relied on different strategies to help them manage symptoms, as is evident by a lack of consensus for statement 26 about knowing when to rest. Women like Darlene, for example, were worried about the symptoms they were experiencing. Three years after having GDM she was also concerned about developing type 2 diabetes because, *"I can't wake up sometimes and the same symptoms I had when I had it and I'm tired, you know. I was tired three days in a row here this week, but I was eating a lot of Halloween candy to get rid of it."* Like Darlene, Diane talked about being tired with GDM and not being able to stay awake with her other young children. She talked in more detail on the emotional highs and lows that only some participants associated with fluctuating blood glucose (BG) levels (21). She said, *"with my daughter, I was constantly yelling or just swearing and I was just – 'oh, this isn't me'. I feel so possessed-like. I'd sleep all the time. I just felt so low. And then, the insulin really helped. I felt like, 'wow! I feel so good.' And then, when it would go high, I'd be mental again."*

Stacey felt very differently while taking insulin. Her comments about the discomfort and worry associated with adjusting insulin levels in the midst of her already challenging life circumstances reflect, like Darlene's admission, a lack of confidence and confusion that translated into an overwhelming anxiety. She talked at length about her experience increasing insulin levels: *"I had a bad headache and I felt like I was in labour*



– *[that's] how I felt. I was in a lot of pain. Really just not well at all.*” The whole process of adjusting her insulin she found “*really, really, really stressful. So I didn't bother [with the insulin]. And my headache went away. So I went back to what I was giving myself before. I didn't give myself insulin for two days. Then I read on the Internet that too much insulin causes headaches, drowsiness, dizziness so just went back to what it was before.*”

**Outcomes.** A lack of agreement within the area of outcomes also revealed variation in the way participants talked about risks associated with GDM. Several women expressed their frustration and confusion about the postpartum diabetes information they received. Perhaps as a result, their interpretation of outcome messages again relate to personal experiences with both GDM and type 2 diabetes, as do many of the other statements listed in Table 4.6. Deb commented that since she had GDM, she assumed she would have diabetes for the rest of her life, but when she asked her doctor, “*they said it goes away after, but when I asked them if I will have diabetes when I get older, they're like, 'I don't know'*”. These comments correspond to the lack of consensus observed for statement 22. More than half of the participants felt that women who had been diagnosed with GDM would have it with all of their subsequent pregnancies. At the same time women shared the opinion that GDM is temporary and goes away postpartum. According to Linda, who had been diagnosed with GDM twice she knew, “*the moment I have the baby, I have no more blood sugar problems. It's like done, gone – instantaneous.*”

There was also considerable variation among participants about whether or not GDM could pose serious risks to their babies. Several women were angry and confused about the potential health consequences, as is reflected by the lack of consensus for statements 25 and 30. As Darlene said after the birth of her third daughter, “*I didn't know*

*how serious it was and I still don't know the seriousness of it!"* Diane similarly complained she wasn't consistently told by her health care providers about the potential for adverse perinatal outcomes. She recalled that when people found out she had GDM, they would often say, "*oh, it's gestational. That's so dangerous for your baby!*" She would respond, "*well, how is that? I don't know. I don't know how dangerous it is for my baby. I don't know. I mean, gestational diabetes, in general. I don't know if it is dangerous 'cause I've never been told if it is or it isn't!*"

Carole, like Diane, was also pregnant at the time of her interview, and had already experienced GDM three times. Perhaps because of her level of experience, her comments reflected a different understanding. She talked about outcomes this way: "*the baby will come out big. You could even have your baby early. Your baby can end up sick staying in the hospital for so many months, days.*" Although this variation in interpretation of risk was obviously based on living with diabetes herself, Carole's mother and Aunty exposed her to the risks associated with type 2 diabetes. When asked how she learned so much about diabetes she explained, "*I just really watch; I really pay attention about it. I don't ignore it 'cause I know it could take me down 'cause it already gave my Aunty Cathy blindness. It already took one of her kidneys. She's extremely overweight [and] doesn't follow the rules. She can't even walk no more because she's so big.*"

**Possible sources of variation.** Given the weak consensus for this sample of Aboriginal women from a variety of backgrounds, QAP was used to test for significant differences between sub-groups of participants (as used by Garro, 1986 and 1996 and Marchessault, 2001). Based on posthoc hypotheses, analyses were conducted for age, parity and place of residence growing up. The alternative hypotheses being tested were

that correlations within sub-groups would be higher than elsewhere. Although the small numbers of participants make it difficult to substantiate with authority, the findings of the QAP support the presence of measurable differences between women of high (3 children or greater) versus low parity (less than 3 children) with a  $p$  value of  $< .000$  achieved. The results also indicate a significant difference ( $p < .000$ ) between participants who grew up in Winnipeg versus those who grew up on-reserve, despite a sample of only seven women in each location category (see Table 4.7).<sup>5</sup> There was no significant difference between groups of women based on age.<sup>6</sup> To further assess variation, consensus analysis was again performed for sub-groups of women who were statistically different from each other based on parity and location growing up. Only the results for parity will be presented here because of the small sample sizes of participants from Winnipeg and those from reserve. According to Weller and Romney (1988), although the reliability of aggregated responses is a function of both sample size and agreement among participants, to classify at least 85% of statements correctly at the .95 level of confidence, 10 participants are necessary, given an average competence of .5. As indicated in Table 4.8, there is no evidence to support cultural consensus for the two groups of 10 women based on number of children. Again the two ratios for the first to second eigenvalues are less than three and the mean consensus factors are low, demonstrating minimal sharing.

When comparing these trends with the results of the explanatory model interviews 55% of participants had never met another woman with GDM. Looking again at sub-groups based on parity, the more children women had (3 or greater), the less likely they had met someone with GDM. For this group of women, 73% had never met a woman

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5 No significant difference was found with a third group of seven women from rural Manitoba ( $p < .680$  versus urban;  $p < .260$  versus reserve).

6 The  $p$  value was .17 comparing those aged 30 and older versus women 29 and under.

with GDM compared to only 35% of women who had less than 3 children. This lack of sharing among women with a similar number of pregnancy experiences may reflect social isolation. Aboriginal women with a greater number of children do not always have the opportunity to get out of the home as frequently, and aside from immediate family living in the city, may only have regular contact with prenatal health care providers. During the semi-structured interviews, several women talked about living with GDM in isolation. Sharon said, *“because if you don’t know anyone else who’s had it, you don’t know how you’re feeling, if how you’re feeling is normal.* Anita’s comments were similar: *“you feel so lonely if you’re going through it all by yourself, nobody else understands it, what you go through.”*

As discussed in the section on shared biomedical understandings, so much of what this group of women knew about GDM was based on knowledge from personal experience or information they were able to glean from contact with health professionals. During another interview at a coffee shop, Terri ran into a long-time friend. When her friend found out Terri was participating in a study on gestational diabetes, she admitted she knew she currently had GDM, but did not want to do the testing since she had GDM with three previous pregnancies without any perceivable complications. Terri later discussed her friend’s inaction and admitted that although they met frequently neither one knew that they had GDM. Terri explained, *“it’s just a subject that – one of the subjects that don’t come up.”*

Gestational diabetes, unhealthy eating practices and outward appearance are described as being closely tied to self-worth and how women are perceived socially or externally – not only within their families, but in the community overall. It is a negative

influence on self-esteem and self-perception as women and mothers. At the time of her diagnosis Doris said, *“I thought my life was just totally over and that was it and I was just going to mush away. I didn’t know what it was, [but] you have this image: ‘oh, she has diabetes.’ You see her and she’s kind of overweight and chunky. I always look in the mirror and it’s like, ‘yeah, I’m looking kind of chunky myself.’ But you don’t recognize it over time. It’s like, ‘what’s wrong with you? There must be something wrong’.”*

This judgment and negative perception of diabetes for some of these participants may help to explain why an overall lack of sharing was found from the cultural consensus analysis. However, GDM is still a relatively rare condition, so many women in Winnipeg may never have experienced it. There also could be a lack of sharing stemming from societal, cultural as well as self-perceptions having to do with GDM. Why Aboriginal women do not talk about GDM with each other seems to reflect the stigma, blame and denial that are so closely connected to diabetes, especially in Aboriginal communities. Based on her experience as a single mother living in Winnipeg for many years, Faye talked about these concepts in detail and explained how women diagnosed with diabetes can interpret it as a punishment:

*I think it’s very important to educate people that it’s not something that we did, that God is not punishing us. It maybe sounds foolish to say that but some people do believe that. What people say you can generally determine whether this person is being in denial and being ashamed. You can probably determine that in other areas of their life, there’s something serious that’s occurring. And this is why I say there has to be a holistic approach in dealing with diabetes. Because it’s not just the physical state of being, which is diabetes; but it’s also emotional, spiritual. Saying that and looking at the history of Native people, they’ve gone through such a horrific experience in the past— residential schools and being separated from families. So there’s a whole generational gap. It doesn’t take a whole lot of guess work to wonder how it all could have happened. So I think diabetes is not just a disease in itself, as far as the physical well-being. As I said, it’s all holistic. It’s all tied into how people feel about themselves, how they perceive themselves. And that’s why it’s seen as a shame – you know, of having diabetes because*

*we have to confront these issues that's causing them to be ashamed of one more thing that's causing them to look bad or be looked at as a bad person.*

## **Discussion**

Given the cultural consensus analysis results for this study, there is enough evidence to support the assumption of weak consensus or shared understandings about gestational diabetes for this group of Aboriginal women. Ideas from statements most commonly shared, however, seemed to be framed around biomedical concepts or health education messages received from care providers. The treatment of GDM through lifestyle adjustment was commonly discussed during the qualitative interviews as well. Considerably more variation was evident from the responses to cultural consensus statements for the categories of etiology, course/symptoms and outcomes of GDM. In their open-ended comments, women similarly expressed their confusion and frustration over conflicting concepts related to GDM causation, its complications, associated sensations and short-term as well as long-term outcomes. As their interviews highlighted, a significant proportion of participants expressed confusion about the potential seriousness of having diabetes while pregnant. There was considerable variation in their interpretation of risk. Women's references to symptoms over the course of their experience with GDM also varied substantially, although feelings of anxiety were expressed most consistently. Measurable differences between sub-groups of participants were determined using the QAP. Women of higher parity and urban versus reserve location were found to be significantly different in their responses to the consensus statements, especially for course, treatment and outcomes. Cultural consensus was not achieved, however, within either of these groups of women, perhaps simply reflecting the diversity of the sample of Aboriginal women or the small sample sizes.

However, based on the weak overall consensus results and EM interviews, it also seems plausible that there is a lack of personal sharing or shared experiences between women. Particularly for the group with a greater number of children, few had ever met anyone else with GDM. Much of what the overall group knew about gestational diabetes was therefore gleaned from personal experience or interaction with prenatal or endocrine health professionals. Results of the EM interviews also suggest the stigma that is associated with GDM, which may limit informal discussions on the topic. Women talked about this negative perception that both frightened and further isolated them socially in a more individualized urban environment. Diabetes was associated with injections, complications and death resulting from not being responsible, or taking care of oneself. As Faye stated, GDM may also be viewed as a punishment or shame.

Opinions expressed from the semi-structured interviews make clear that at least for this group of participants, GDM is not a frequent topic of conversation. Very few women had ever met another woman with GDM. These circumstances may help to explain the lack of cultural consensus for this smaller sample of Aboriginal women. According to Garro, culture is something that is learned, and what is learned best and therefore shared, “are the things people communicate” (1986; p. 353). What appears to be learned most consistently in this study, are ideas or information that have been communicated to Aboriginal women by their health care providers, not from each other. It does not appear that women talk to each other about personal experiences with GDM. Living in a large urban centre can also be isolating to women compared to those who have grown up in a smaller reserve community. There is little opportunity for expectant or new mothers to meet each other in a comfortable setting to discuss their personal

experiences or perceptions of an “at risk” pregnancy (Heaman et al., 2004).

Very little qualitative work has been done on the topic of diabetes and pregnancy among Aboriginal populations. Smith-Morris has perhaps done the most extensive ethnographic work among Pima women in Arizona. Although her participants were accessing health care on their reservation, there are some parallels in their experiences. Discussions of gestational diabetes by Pima women were generally influenced by biomedical, traditional and popular notions (Smith-Morris, 2006a). Those who had completed prenatal education classes where diabetes education was provided, more readily adopted biomedical explanations for GDM. Information transferred by care providers during prenatal appointments was found to be the most influential with regard to women’s perceptions and interpretation of messages relayed (Smith-Morris, 2005), as seems to be the case for Aboriginal women seeking care in Winnipeg. However, for women living in the Pima community, a primarily monocultural rural setting where type 2 diabetes is endemic, there is perhaps greater opportunity to develop more collective banks of experience or memory in a social context that may or may not be aligned with biomedical accounts of diabetes (Smith-Morris, 2005). Diabetes is conceptualized primarily in terms of its most visible complications which is confusing when associated with pregnancy, which is a celebrated event. It also increases young women’s sense of vulnerability to the disease as well as their level of frustration with care providers who do not sound precise or reliable in the risk information they are providing (Smith-Morris, 2005; Smith-Morris, 2006a).

Aboriginal women accessing care in Winnipeg had similar experiences observing family members with complications resulting from type 2 diabetes. Many also expressed



their confusion and frustration over education messages, most notably those related to GDM outcomes and potential risk for mother and child. Like Pima women they seemed to express the need to develop, what Smith-Morris refers to as, a “linear sense of diabetes”, or of its inevitability so the urgency or futility of their circumstances could more accurately be gauged (Smith-Morris, 2006a; p. 198). There was also a stigma against speaking about diabetes in certain Pima families. Several participants spoke about diabetes as the disease that has a “*really bad stigmatism [sic] to its name*” (Smith-Morris, 2006b; p. 78). Like the current study, there was also an element of morality or judgement surrounding Pima women to follow lifestyle guidelines with often little social support. Management of GDM was described as a solitary experience with families and friends typically not changing their behaviours in solidarity. For the Pima, diabetes is “the disease that isolates or differentiates a person” and accordingly is not often talked about in a culture that values togetherness and sociability (Smith-Morris, 2006b; p. 148).

In response to diabetes exposure it is interesting to note that Pima women’s ideas and interpretations of risk would change over time. After women had their first child, they were more willing to miss prenatal appointments based on their own interpretation of physical symptoms or bodily sensations. They appeared to develop a greater confidence and expressed a greater knowledge of pregnancy based on their own experience (Smith-Morris, 2006a). This may also explain why Terri’s friend was not concerned about having GDM because she was already aware of it in her body after having gone through it without any observed effect or benefit. These explanations may partially explain the significant differences determined by the QAP between groups of participants based on parity, not age. Multiparous women may not necessarily avoid care,

but perhaps have different perceptions of risk and control than women who are pregnant for the first time.

Other qualitative investigations with population groups in the United States, Canada and Sweden provide some similar and yet divergent thematic results (Hjelm et al., 2005; Hjelm et al., 2007; Lawson and Rajaram, 1994). Participants in Evans and O'Brien's (2005) Canadian study described their diagnosis of GDM as shocking and something that was not anticipated. It threatened their autonomy and sense of control over their lives, although it was not necessarily associated with the severe complications Aboriginal women describe. The mainly Caucasian women in the study were motivated to take appropriate actions in managing their GDM because, like the participants in the current study, many felt blamed or responsible for developing diabetes while pregnant. Physical symptoms were also intangible which left women feeling anxious and vulnerable. Additional instability and confusion were reported in light of the perceived imprecise nature of prenatal tests and education messages regarding outcomes. For some women having GDM presented a negative stigma that was embarrassing as it signified they were unhealthy.

Middle-Eastern and Guatemalan immigrants who were interviewed in Sweden and Detroit, Michigan, however, seemed closely aligned in their described experiences with GDM. Both groups of women referred to a social isolation adjusting to life in a culturally foreign urban centre. Many were separated from families and extended support networks, with small children to care for at home (Hjelm et al., 2005; Hjelm et al., 2007; Kieffer et al., 2002). Middle-Eastern women had less self-perception of bodily symptoms as well as a lower degree of self-efficacy compared to Swedish women with GDM. They

also discussed social factors more frequently as being important for the health of mother and baby, such as emotional support from healthcare providers and family members. Swedish women talked about the importance of individual factors such as exercising and eating a healthy diet, and did not accept the condition of GDM as chronic. They actively searched for information to prevent the development of type 2 diabetes. Like many of the Aboriginal participants in this study, Middle Eastern women had less perceived behavioural control in adapting to health care advice, and did not frequently discuss their own role in lifestyle treatments prescribed (Hjelm et al., 2005).

Kieffer and colleagues (2002) suggest that beliefs about etiology, personal susceptibility and modifiability of risk when it comes to diabetes, may all influence women's motivation to undertake lifestyle changes. The degree of perceived control of self-efficacy for these groups of minority women with GDM may also be related to a higher perceived susceptibility to and severity of diabetes, as well as a higher awareness or risk. Migrational, transitional or stressful life experiences, it has been suggested, may negatively impact the sense of control women have over their lives and health status (Hjelm et al., 2003). As Faye referred to the legacy of residential schools and their continuing impact on the self-awareness and consciousness of Aboriginal women diagnosed with GDM, this collective experience has potentially combined negatively with the cultural and social isolation felt for many in an unfamiliar urban setting. Prenatal knowledge from relatives and friends will less likely be transferred, as was found in another Manitoba study comparing the prenatal dietary experiences of two generations of First Nation women living on-reserve (Neufeld, 2003). These circumstances may be most

challenging for Aboriginal women with GDM who feel stigmatized or further marginalized by their condition.

In recent years, a significant amount of literature has been published on the experiences of individuals with type 2 diabetes. Although the various population groups studied and the experience of GDM may not be directly comparable to the group of participants in this study, there are other overlaps. Garro's work in Manitoba First Nation communities used the explanatory model framework and cultural consensus analysis to describe individual accounts of living with type 2 diabetes (1995 and 1996). Shared cultural knowledge was established for each of the three participating communities (Garro, 1996), however, there was considerable variation also reported (Garro, 1995). Two alternative models of diabetes causation were described by participants. Referred to as the "contaminated food model", the first position implied a broader social context of the disease. The other perspective pertained to biomedical teachings that place blame or suggest individual responsibility for developing type 2 diabetes (Garro, 1995). It is interesting that women with GDM in the current study most consistently discussed biomedical teachings and individual responsibility related to the etiology and management of their condition, which similarly represents views associated with teachings from health professionals.

Sunday and colleagues (2001) have argued that diabetes is a collective problem and that lifestyle choice should not be blamed on individuals. For Aboriginal groups they are related to macro-political forces as well. According to Garro, by blaming the individual, a biomedical perspective also "excludes the broader social context of the disease" (1995; p. 45). The exclusivity of biomedical messaging in diabetes treatment and

management does not take into account socially-produced or naturally occurring risks. The ability to manage diabetes is considered a reflection of the ability of the self to be successful and failure therefore implies shame (Sunday and Eyles, 2001). There are social consequences in addition to the more overt or visceral complications of diabetes. Aboriginal participants from other studies in Ontario and Manitoba have referred to the social rather than the physical consequences of diabetes and describe feeling “ashamed” of their diabetes. All the negative perceptions associated with diabetes significantly add to their levels of stress (Iwasaki et al., 2004; Sunday and Eyles, 2001; p. 646). Diabetes symbolizes a loss of freedom and danger that further ostracizes Aboriginal individuals living in urban circumstances, thereby contributing to their physical, emotional, social and cultural isolation.

### **Recommendations and Conclusions**

Although varied in their understandings, participants in this study expressed the need for a clearer understanding of what it means to have GDM. Aboriginal women have a unique perspective compared to the general population including health care professionals who have not been exposed to diabetes in the same way. Smith-Morris has stated about Pima women’s experiences that, “rather than driven by biomedical knowledge, it was the women’s experiences with health events that informed their decisions about healthy behaviors and the meanings of signs and symptoms” (2006a p.200). Women in this study with greater experience were similarly more confident in their opinions of symptom and risk as well as their personal approaches towards GDM management. However, there is also an overall need for more effective education messages and assessment of risk perceptions to address misconceptions and stigma for

Aboriginal women with GDM and their caregivers. Positive influences are urgently required to support healthy living and instill pride instead of the fear and self-blame that lead to examples of poor self-esteem. For the entire group of participants gestational diabetes was a significant part of their lives and needs to be incorporated as part of a more accepting and egalitarian world to reduce the shame and guilt associated with a biomedically-influenced individual responsibility.

Even though cultural consensus was established for the overall group of participants, the results point mainly to a shared understanding of biomedically-based prescriptions for the treatment or management of GDM. Further analysis using the QAP, combined with the analysis of the semi-structured EM interviews suggested possible explanations for the variation. Women of higher parity were found to be significantly different in their responses compared to those with fewer children. It was also postulated that residence location could account for difference. Initial perceptions of GDM could act as indicators of motivation and management success. Results from the EM interviews also point to a lack of personal sharing between Aboriginal women on the topic of GDM, perhaps as a result of a negative perception or because of its more recent rising prevalence.

There is a need for further research to more definitively explain these results. Further testing may be more effectively achieved with larger numbers of participants to allow for more definitive QAP results with perhaps less diverse populations, such as First Nation women with GDM living on-reserve or looking more specifically at Métis women's experiences. It is important, however, to involve Aboriginal women living as a minority group within an ethnically diverse urban setting since results from this

exploratory study have suggested these experiences may be unique from their counterparts living on-reserve or other rural settings. It is also imperative that programming be created with the input from the Aboriginal community to establish support groups exclusively for women with gestational diabetes to enhance peer-based understanding of symptoms and risk as well as reduce their sense of anxiety and isolation.

Based on the results of the cultural consensus analysis it is difficult to draw strong conclusions that would support the existence of a shared cultural model for GDM. It is also difficult to extend the findings of this investigation and apply them to the larger population of Aboriginal women who have experienced GDM in the urban setting of Winnipeg because of the method of participant recruitment. Sub-groups of women based on attributes such as childhood residence were also too small to make valid comparisons even though significant results were established with the QAP (Weller and Romney, 1988). However, this investigation is believed to be the first qualitative study on the topic of gestational diabetes among Aboriginal women accessing care in a large urban centre. Findings warrant a continued research focus on this population group as well as specialized programming to support socially isolated women and their families.

Table 4.1: Sample Explanatory Model Questions

<b>Explanatory Model Category</b>	<b>Sample Questions</b>
Onset	Can you tell me about how you found out you had gestational diabetes? When did it happen?
Etiology	What do you think caused you to develop gestational diabetes?
Course of Illness/Symptoms	Do you ever think that you will have diabetes again?
Pathophysiology	If you had to explain to someone how gestational diabetes works, how would you describe what happens inside your body?
Treatment	How do you think diabetes during pregnancy should be treated?
Prevention	What do you think a woman can do so she won't get gestational diabetes?



Table 4.2: Participant pseudonyms, diabetes, obstetric and location status at time of interview

Pseudonym	Diabetes Status	Prior Pregnancies	Residence
Darlene	GDM with last pregnancy, three years ago	3	Winnipeg
Tracy*	GDM with previous pregnancy, 7 months ago	10	Winnipeg
Alice	Currently type 2 after 4 <sup>th</sup> pregnancy with GDM, 4 years ago	5	Winnipeg
Marion	Currently type 2 after 4 <sup>th</sup> pregnancy with GDM, 1 year ago	4	Winnipeg
Sharon	GDM with first pregnancy 1 year ago	1	Rural MB
Pam	GDM with first pregnancy 4 years ago	2	Winnipeg
Dawn*	GDM currently	1	Winnipeg
Deb	GDM with previous 2 pregnancies, 1 and 2 years ago	5	Winnipeg
Carole*	Currently has type 2 after 3 <sup>rd</sup> pregnancy with GDM, 2 years ago	3	Reserve
Terri*	GDM with prior pregnancies and currently	3	Winnipeg
Eva	GDM with last pregnancy, 2 years ago	3	Winnipeg
Anita	GDM with last pregnancy, 3 years ago	4	Winnipeg
Nancy	GDM with first pregnancy, 3 years ago	2	Winnipeg
Sandy*	Currently type 2; GDM with last 2 pregnancies, 1 and 2 years ago	3	Winnipeg
Tricia	GDM with last pregnancy, 6 months ago	2	Winnipeg
Elaine*	GDM with last pregnancy, 3 years ago	1	Winnipeg

Linda*	GDM currently and with last pregnancy 2 years ago	4	Winnipeg
Cindy*	GDM currently; 2 <sup>nd</sup> trimester	2	Reserve
Faye	Currently type 2, GDM with last pregnancy, 2 years ago	3	Winnipeg
Tina*	GDM currently	0	Reserve
Lori*	GDM currently and with last pregnancy, 11 years ago	1	Winnipeg
Amber	GDM with last pregnancy, 3 months ago	1	Winnipeg
Lorna*	GDM with current pregnancy	2	Winnipeg
Doris*	GDM currently	0	Winnipeg
Stacey*	Currently type 2, GDM with last 2 pregnancies, 2 and 4 years ago	4	Winnipeg
Veronica*	GDM currently	1	Winnipeg
Claire*	Currently type 2; GDM with last 2 pregnancies, 1 and 3 years ago	2	Reserve
Lena	GDM with last 2 pregnancies, 3 years and 5 months ago	7	Winnipeg
Diane*	GDM with current and last pregnancy, 3 years ago	4	Winnipeg

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\* Participant pregnant at time of interview

Table 4.3: Demographic characteristics of participants

Characteristic	Aboriginal women (n=29)
Median Age (years) (range)	30 (18-43)
Education Level Attained	
Elementary school	2
Some high school	9
Completed high school	6
Some post-secondary	11
Completed post-secondary	1
Annual Income (\$)	
5,000-14,999	9
15,000-24,999	10
25,000-34,999	6
35,000-45,999	2
> 50,000	2
Marital Status	
Common-law	13
Married	5
Single	11
Occupation	
Homemaker	17
Private sector employee	5
Government employee	2
Unemployed	4
Student	1

Table 4.4: Comparison of consensus factor loadings on the overall sample and for each separate domain

Domain	Consensus factor			Eigenvalue ratio	
	N	Mean	SD	1 <sup>st</sup> to 2 <sup>nd</sup>	2 <sup>nd</sup> to 3 <sup>rd</sup>
Etiology	21	.20	.39	1.06	1.36
Course of Illness	21	.47	.29	1.77	1.34
Treatment	21	.58	.22	2.24	1.30
Outcomes	21	.28	.50	2.36	1.20
Prevention	21	.50	.48	2.14	1.60
<b>All</b>	<b>21</b>	<b>.48</b>	<b>.18</b>	<b>4.12</b>	<b>1.04</b>

Table 4.5: Proportion of agreement with consensus position for statements meeting binomial criterion\*

Statement	Yes/No	% Agreement	EM Category
1. Do you think that going for walks can help women with GDM keep their blood sugars in control?	Y	.95	T
2. Do you think that pregnant women with GDM should just not eat anything as a way to keep their blood sugars from changing?	N	.95	T
3. Do you think women are more likely to get GDM if they are overweight?	Y	.90	E
4. Do you think enough is known about GDM to prevent it?	N	.90	P
5. Do you think GDM can be passed down from a mother to her daughter?	Y	.86	E
6. Do you think GDM can happen to women because of the way they eat?	Y	.86	E
7. Do you think that eating foods with a lot of sugar in them makes women with GDM feel tired?	Y	.86	C

8. Do you think that GDM can change the colour of a woman's skin when she is pregnant?	N	.86	C
9. Do you think that if you can't feel that your blood sugar is high you do not need to do anything, like check your blood or take your insulin?	N	.86	T
10. Do you think if a woman eats mostly meats, she can keep her blood sugar lower?	N	.86	T
11. Do you think women can get GDM from not being active or just sitting around during pregnancy?	Y	.81	E
12. Do you think that for pregnant women with GDM, stress can make blood sugar levels high?	Y	.81	C
13. Do you think it can hurt the baby if a woman eats too much sugar when pregnant with GDM?	Y	.81	O
14. Do you think that women may react to having GDM by being worried or anxious during their pregnancy?	y	.76	C
15. Do you think that if a woman has had GDM she will be more likely to get type 2 diabetes in a few years' time?	y	.76	O
16. Do you think that women who have had GDM should worry about their children getting diabetes in the future?	y	.76	O
17. Do you think it is okay for pregnant women with GDM to eat whatever they are craving?	n	.76	T
18. Do you think there is nothing to be done to prevent diabetes because it comes and goes whenever it wants to?	n	.76	P

\* All Y/N statements met criterion for consensus analysis and significance for the binomial test at the level of  $p < .01$ ; all y/n at  $p < .05$ . Statements are listed from high to low consensus.

Table 4.6: Proportion of agreement with consensus position for statements **not** meeting binomial criterion\*

Statement	Yes/No	% Agreement	EM Category
19. Do you think if pregnant women eat healthy they can prevent GDM?	y	.71	P
20. Do you think if a woman eats too much when they are pregnant they can get GDM?	y	.67	E
21. Do you think when women have GDM their blood sugars may cause them to be extra emotional?	y	.67	C

22. Do you think gestational diabetes is temporary and goes away after the baby is born?	y	.67	O
23. Do you think that being active can prevent GDM?	y	.67	P
24. Do you think more Aboriginal women are getting GDM because of poverty?	y	.62	E
25. Do you think that if a woman does not control her GDM her baby might be born too early?	y	.62	O
26. Do you think that a woman with GDM should rest when their blood sugars are high?	n	.62	T
27. Do you think that it is best for women with GDM to trust their own judgment when making decisions about caring for themselves and their baby?	n	.62	T
28. Do you think if women avoid eating certain foods like sugar, white bread and fast foods they won't get GDM?	n	.62	P
29. Do you think most Aboriginal people eventually get diabetes because it runs through their families?	y	.57	E
30. Do you think when a woman is diagnosed with GDM she will have a big baby?	n	.57	O
31. Do you think if a woman has GDM there is nothing she can do to stop it, even if she follows a healthy diet?	n	.57	E
32. Do you think a woman's body changes after having GDM and she may have more trouble losing weight?	n	.57	O
33. Do you think women who have had GDM will get it with all their other pregnancies?	y	.52	E
34. Do you think if women are older when they get pregnant they can get GDM more easily?	n	.52	E
35. Do you think that when blood sugars are high, women with GDM may notice their eyes hurting?	n	.52	C
36. Do you think when people are more active their bodies produce more insulin?	n	.52	C

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\* All statements did not meet criterion for consensus analysis and significance for the binomial test at the level of  $p < .05$ . Statements are listed from high to low consensus.

Table 4.7: Consensus analysis results for participants based on childhood residence

Location	Consensus factor			Eigenvalue ratio	
	n	Mean	SD	1 <sup>st</sup> to 2 <sup>nd</sup>	2 <sup>nd</sup> to 3 <sup>rd</sup>
Urban	7	.54	.179	3.233	2.482
Reserve	7	.49	.165	3.061	1.437

Table 4.8: Consensus analysis results for participants with < 3 children versus those with 3

Parity Group	Consensus factor			Eigenvalue ratio	
	N	Mean	SD	1 <sup>st</sup> to 2 <sup>nd</sup>	2 <sup>nd</sup> to 3 <sup>rd</sup>
<3 children	10 <sup>a</sup>	.50	.083	2.75	1.64
3 children	10	.48	.238	2.61	2.75

<sup>a</sup> One participant was excluded from this group as an outlier based on previous analyses and to achieve a square matrix for the QAP.

Figure 4.1: Structure matrix used to test for differences between participants with higher (H) and lower (L) parity

	H	H	H	H	H	H	H	H	H	H	H	L	L	L	L	L	L	L	L
H	0	1	1	1	1	1	1	1	1	1	1	0	0	0	0	0	0	0	0
H	1	0	1	1	1	1	1	1	1	1	1	0	0	0	0	0	0	0	0
H	1	1	0	1	1	1	1	1	1	1	1	0	0	0	0	0	0	0	0
H	1	1	1	0	1	1	1	1	1	1	1	0	0	0	0	0	0	0	0
H	1	1	1	1	0	1	1	1	1	1	1	0	0	0	0	0	0	0	0
H	1	1	1	1	1	0	1	1	1	1	1	0	0	0	0	0	0	0	0
H	1	1	1	1	1	1	0	1	1	1	1	0	0	0	0	0	0	0	0
H	1	1	1	1	1	1	1	0	1	1	1	0	0	0	0	0	0	0	0
H	1	1	1	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0
L	0	0	0	0	0	0	0	0	0	0	0	1	1	1	1	1	1	1	1
L	0	0	0	0	0	0	0	0	0	0	0	1	0	1	1	1	1	1	1
L	0	0	0	0	0	0	0	0	0	0	0	1	1	0	1	1	1	1	1
L	0	0	0	0	0	0	0	0	0	0	0	1	1	1	0	1	1	1	1
L	0	0	0	0	0	0	0	0	0	0	0	1	1	1	1	0	1	1	1
L	0	0	0	0	0	0	0	0	0	0	0	1	1	1	1	1	1	0	1
L	0	0	0	0	0	0	0	0	0	0	0	1	1	1	1	1	1	1	0
L	0	0	0	0	0	0	0	0	0	0	0	1	1	1	1	1	1	1	0

## **Chapter Five**

### **Food Perceptions of Aboriginal Women Coping with Gestational Diabetes in Winnipeg, Manitoba**

Gestational diabetes mellitus (GDM) has been defined as glucose intolerance of variable severity with onset or first recognition during pregnancy (Metzger and Coustan, 1998). Rates of GDM appear to reflect the rising incidence and prevalence of type 2 diabetes among Aboriginal<sup>1</sup> populations (Ben-Haroush et al., 2003; Dyck et al., 2010; King, 1998). Reported prevalence rates for GDM range from 11.5 to 12.8% among groups of Aboriginal women in Canada compared to 3.7% in the overall Canadian population (Aljohani et al., 2008a; CDA, 2008; Dyck et al., 2002; Godwin et al., 1999; Harris et al., 1997; Rodrigues et al., 1999). A recent Québec study revealed prevalence rates as high as 14.9% and 27.4%, respectively, among Cree women who were classified at the onset of pregnancy as overweight with a body mass index (BMI) between of 25 kg/m<sup>2</sup> and 30, or obese with a BMI of > 30 kg/m<sup>2</sup> (Brennand et al., 2005).

Excessive weight gain prior to and during pregnancy has been found to increase a woman's risk of developing GDM (Brennand et al., 2005; Hedderson et al., 2008). Few studies, however, exist that examine Aboriginal women's eating patterns. For Aboriginal women in their child-bearing years, higher rates of overweight/obesity have been published with 64% of Aboriginal women being classified as overweight compared to 47% of non-Aboriginal women. These young Aboriginal women (aged 19-30) living off-

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1. In Canada, "Aboriginal" includes status and non-status First Nation, Inuit and Métis people (Frideres and Gadacz, 2008) and will be used throughout this document to refer to the women of self-declared First Nation and Métis backgrounds who participated in this study.



reserve in Ontario and the western provinces, also reported daily caloric intakes that significantly exceeded those of their non-Aboriginal counterparts, with items other than those included in the four main food groups making up 32 % of their average daily intake. Soft drink consumption for Aboriginal women was three times that of non-Aboriginal women in the same age category (Garriguet, 2008).

These troublesome findings are supported by other recent smaller dietary studies with various groups of Aboriginal women that point to poor quality diets and lack of physical activity as contributing to weight issues (Delormier and Kuhnlein, 1999; Harnack et al., 1999; Neufeld, 2003; Powers, 2008; Willows et al., 2008). As Willows (2005) has described, many knowledge and research gaps continue to exist in this area. Food consumption patterns for pregnant Aboriginal women have been significantly overlooked in the published literature. Those studies that exist employ almost exclusively self-reported dietary recall and food frequency questionnaires (Godel et al., 1992; Lawn et al., 1998; Waiters et al., 1998). Although these studies are helpful in documenting dietary patterns, they are not able to address the complexities and meanings behind food choices and behaviours. Use of qualitative methodology is far less common, especially among Aboriginal women experiencing diabetes and pregnancy (Neufeld and Marchessault, 2006; Smith-Morris, 2006) and Aboriginal women in an urban setting (Wilson and Young, 2008). There are no other studies I am aware of that have examined the food perceptions of Aboriginal women with GDM in an urban environment.

Given the lack of research into this area, a qualitative research design was chosen for this study incorporating Arthur Kleinman's explanatory model framework (Kleinman

et al., 1978) to provide Aboriginal women the opportunity to discuss their experiences with GDM. The primary objective in conducting the overall research project was to describe how Aboriginal women receiving prenatal care in the urban centre of Winnipeg, Manitoba, perceive and cope with GDM based on their own explanations of the condition. In this paper I present a thematic discussion of participants' perceptions of food and challenges faced integrating dietary treatment recommendations into their daily lives, while experiencing a pregnancy complicated by gestational diabetes.

### **Methodology**

One of the strengths of qualitative research is the rich and detailed information it can generate in describing, in this case, Aboriginal women's perceptions of food while coping with gestational diabetes. It provides a means of accessing information and issues about which relatively little is previously known (Morse and Field, 1995). Participants are free to express themselves in their own terms (Sunday et al., 2001). Findings are also more descriptive or holistic in nature (Gilchrist, 1997), which is more consistent with Aboriginal worldviews or epistemologies (Ermine, 1995; Smith, 1999). Qualitative research methodology permits the use of interpretive data collection techniques that are more flexible, such as in-depth interviews, which are further characterised by a more equitable balance of control on the part of the researcher (Gittelsohn et al., 1996).

In-depth interviews were the primary method of data collection for this study. Participants' understandings and experiences with GDM were explored using different interview formats. Three separate protocols were designed as part of a larger study to develop a more comprehensive portrait of Aboriginal women's descriptions of their

illness. A discussion of these results including Aboriginal women's experiences with the health care system is located elsewhere (Chapter 6). Next, Kleinman's Explanatory Model Framework (Kleinman et al., 1978) was utilized to conceptualize and understand Aboriginal women's experiences with GDM through open-ended questions framed around five themes: causation, onset, course of the illness, treatment, pathophysiology and prevention. A sixth theme of prevention was added to examine this concept related to GDM, given a lack of investigation into this area. Arcury and colleagues (2004) have suggested the model is sufficiently flexible to incorporate the addition of wellness themes or concepts. Examples of these questions are listed in Table 5.1. Lastly, a more structured fixed-response interview was administered to determine whether or not shared cultural understanding on the topic of gestational diabetes existed among the participants. Results of this consensus analysis also appear elsewhere (Chapter 4).

Recruitment and interviewing began in the November 2006 and continued until September 2007. Participants were recruited through posters in the community, as well as presentations made by the author to prenatal groups and at endocrine or obstetric ambulatory clinics. A diverse volunteer sample of 29 self-declared Aboriginal women who had been diagnosed with gestational diabetes during their current pregnancy or within the past five years was recruited for this research project.

All interviews were conducted by the author. Pseudonyms have been used for the participants to protect their identities, as listed in Table 5.2. Quotes have been edited slightly solely to improve readability (Neufeld et al., 2006).

**Analysis.** During the collection period, all of the interviews were audio-recorded

with the consent of the participants. These audio files were transcribed verbatim by the author with assistance from a hired transcriptionist. The interview transcriptions were then reviewed, along with field notes and summaries for descriptive categories and patterns (Miles and Huberman, 1994). These files were then organized and further coded using NVivo7 (Qualitative Solutions and Research, 2006). The software was used to browse, search and interpret the interview text through the creation of models and memos (Richards, 2005). Thematic analysis was subsequently employed through coding linkages and matrix coding queries that assisted in identifying and categorizing relationships in order to generate theory (Bazeley, 2007).

**Ethical considerations.** The study was approved by the University of Manitoba Health Research Ethics Board, the Health Sciences Centre Research Impact Committee, Health Canada Research Ethics Board, and the Winnipeg Regional Health Authority Research Review Committee. Additionally efforts were made to adhere to the *Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007).

## **Results**

**Participant characteristics.** In total, 30 Aboriginal women were recruited for the study. The response rate was 90%, and the average time for the interview was one hour, 9 minutes. Many participants (43%) preferred to be interviewed in their homes. Women ranged in age from 18-43 years. On average they had three children. Sixteen were pregnant and nine had GDM at the time they were interviewed. While receiving treatment for GDM, 18 of the 29, or 62% of participants were prescribed insulin to manage their

blood glucose (BG) levels. The remaining women were able to control their BG through lifestyle measures, including adjusting their dietary practices according to recommendations received from diabetes educators or dietitians (see Table 5.2 for additional detail). One woman from a northern reserve community had to be excluded from the analysis because it was later determined she had been diagnosed with type 2 diabetes at nine years of age. This brought the sample size to 29. All of the women reported having family members with type 2 diabetes, with over 60% of the participants' own mothers diagnosed with type 2. Half of the participants had moved to Winnipeg during young adulthood, while 30% grew up in the city. Four women were currently living on-reserve, but traveled regularly to the city for prenatal care. Additional demographic data for the participants appears in Table 5.3.

**Life circumstances.** Close to 59% participants had completed high school and 12 (41%) had attended a post-secondary institution. At the time of their interview, only seven women were employed outside the home. Four pregnant women described themselves as unemployed since they had no child-care responsibilities either because they were pregnant for the first time, or they did not have their other children living with them. Seventeen participants were their children's primary caregivers and categorized themselves as homemakers. Eleven women were single parents. The majority had partner support in the home. Five were married and 13 living in a common-law relationship with 38% of partners employed, and 15 families receiving social assistance. The average reported household income was \$24,500 a year.

For those women who were living on their own in the city, with few monetary or

social supports, life circumstances were challenging even prior to their diagnosis with GDM. They often lived in sub-standard housing and unsafe urban neighbourhoods. They reported spending much of their time indoors, especially those with young children, such as Stacey. She described her neighbourhood this way: *“I was raised in this area. I know a lot of people, but this isn’t a very good area. I’d like to get out of here but you need money.”* Women living in these circumstances also moved frequently. Darlene described her current living situation: *“I got no friends around here. I’m living somewhere new and I don’t know anybody. I don’t want to know anybody either. There’s a lot of troublemakers around here. I don’t want to get to know people like that. I know who I need to know.”* A former victim of domestic abuse, Darlene and her three daughters moved to get away from her partner and a woman in her former community who had previously attacked her with a knife. As a result, she said, *“I don’t go out. I suffer from some panic attacks now so I don’t go out too much.”* Nine women, including Darlene, reported they had been victims of violence.

Other women described difficult experiences that influenced their living circumstances, as well as their overall emotional perspective and mental health. Sixteen participants talked about traumatic events that led to their displacement. Alice, for example, described her reasons for leaving the reserve: *“the awful thing about living in the reserve is most people, their addictions. I just don’t like to live in that environment and see my people suffer like that.”* Several women had experienced the loss of a child or children. Three mothers lived through their child’s death, four had had children apprehended by Child and Family Services (CFS), and eight had lost children during

pregnancy. Some had gone through a combination of traumatic events. Dawn revealed: “*I lost a child about seven years ago, and I’ve had a lot of miscarriages these past two years, about four or five.*” Ten women were also raised in foster care, five from birth, including Dawn. Prenatal care experiences may understandably be overshadowed by anxiety or fear for this group of participants, even prior to the development of GDM or being classified as having an “at-risk” pregnancy.

**Treatment experiences.** As part of the explanatory model interviews, women were asked about their experiences accessing prenatal and endocrine health care services. Seven of the 23 semi-structured interview questions were framed around the topic of treatment. Women were asked about the advice they received from their care-givers, their impressions on what was most valuable, and changes they would like to see for other women in the same circumstances. They were also asked about their own management practices. Women taking insulin, often described the process as “*frustrating.*” Terri really disliked having to use needles, but was told, “*I don’t have a choice.*” She also explained that trying to keep her BG within the required range was difficult. She said, “*trying to keep it under control, it’s getting aggravating sometimes because it doesn’t always work.*” Terri also felt she had little control over her food choice while on insulin: “*pretty much a lot of things bring it up. I found you pretty much got to eat like a mouse to keep it down.*” Sandy was also taking insulin and described a similar experience, feeling unable to control of her BG levels. She explained that early in her pregnancy she changed her diet, and “*my sugar was okay.*” During her second trimester she started on insulin, and her readings were erratic with what she ate not resulting in control: “*if I don’t eat*

*anything, it still just goes up!”*

Women who did not have to self-administer insulin injections while pregnant considered themselves fortunate. As Sharon said, *“I was lucky because I was able to control my sugar levels through diet rather than having to do the insulin.”* She went on to say that it was still *“hard to manage”* her GDM because she *“barely ate anything”*, and she empathized with other women who used food exclusively as a treatment. She said, *“it takes a lot of willpower, and it’s a lot of change for someone to change their diet when they find out they’re diabetic like that. I can’t imagine people that don’t have access to proper foods to change their diet, ‘cause that’s a big thing.”* Sharon and other participants were aware, for women with GDM managing and maintaining control over dietary behaviours is very difficult, and that food plays a pivotal role in the treatment for GDM, whether or not insulin is being used. Behaviours, perceptions and habits around food have been established prior to pregnancy and often act as barriers. As Sharon alluded to as well, particularly for women who are food insecure or isolated, overcoming the complexity of food access as well as acquiring the treatment knowledge to effectively manage GDM are challenging undertakings.

**Food and gestational diabetes.** Whether or not they were managing their GDM with insulin, by far the most common topics of conversation during the semi-structured EM interviews were food and eating practices. All of the women discussed various adaptation schemes or strategies they utilized for adjusting their eating habits to comply with a health care providers’ or family member’s recommendations. These initial discussions arose primarily as direct responses to questions about prescribed treatment



that were included in the EM interview format. Additionally, many mothers and mothers-to-be talked about food preferences or cravings during their current and previous pregnancies. Other common themes were the fears or anxieties women felt about the subject of food. Participants also expressed their confusion and frustration over the dietary education messages received mainly through nutrition counseling and diabetes education. A complete summary of eating behaviour themes most commonly raised by women according to specific attributes is included in Table 5.4.

***Instability.*** Control over eating habits when food is used as treatment appears to lead to a sometimes unhealthy focus and stressful relationship with food for women experiencing GDM. For a number of women the prescribed diet of several small meals per day to help control blood glucose levels led to frustration, worry and fluctuations in food intake. Faye found altering her usual meal patterns “*very stressful*” because she was used to eating “*one big meal*” that would sustain her for an entire day. Other participants protested against preparing more frequent meals because they were not always hungry. Diane complained that, “*it’s such a struggle to sit here and have to eat.*” However, she later admitted that during the earlier part of her pregnancy, “*what I was eating was not good*” and would also eat a meal only once a day, in larger quantities than recommended. She said somewhat defensively, “*I’m not a big eater but I eat more than 1 cup. I mean, ‘hello, that’s my only meal I eat a day!’*”

For other women struggling to gain control over food or food habits, living with GDM led to further irregularity in eating styles and decreased nutritional quality of items consumed. As Marion described, “*there are times when I just don’t want to eat at all, but*

*I would force myself to eat when I would get shaky and numb.”* She also admitted that when pregnant with GDM she, *“had a bad habit of eating junk food, sweets. Like I wouldn’t really care for eating a meal, I would be okay, I’m going to go buy chips and dip and pop.”* Several other women mentioned that they *“didn’t feel like eating”* while they were pregnant with GDM. Morning sickness was sometimes to blame, but for others these patterns continued throughout the pregnancy. Veronica complained, for example, that for her entire pregnancy, *“salads get me sick and I can’t drink milk.”* She had *“tried to eat differently”* after being diagnosed with GDM. Moving back to Winnipeg after breaking up with her boyfriend, she was trying not to eat *“so much take-out”*, but confessed, *“I’d rather have something fried.”*

Instances of overeating, or binging on foods of low nutritional quality, were discussed by several women with GDM, whether or not they were pregnant at the time of the interview (see Table 5.4). Often these admissions took on a secretive tone as Sandy illustrated one such practice that seemed to be common in her family and among women she knew who would travel to Winnipeg from her reserve community in the north. She whispered as she described that while in the city women would often *“go shop for themselves to take back home, and they go look in their bags and find some sweet stuff, they go hide in their room or in the stores to go eat it.”* Since recently becoming pregnant she was *“eating healthy stuff”*, but after gaining four pounds in one month her mother joked with her and asked, *“well, what you been hiding in your room? What have you been eating there?”*

Secretive behaviours were described by other participants as they were attempting

to conform to health care providers' recommendations. Diane's comments about fluctuating food and weight patterns, like Sandy's, sounded routine as she talked about her food struggles. Many of her admissions were cause for concern, however, as she described the drastic means she used to control her blood glucose levels while pregnant:

*What I used to do for my daughter was – because my husband's not fat but he's an eater. He's like, 'let's go to a buffet'. I'll be like, 'well whatever'. You know? You're not going to take a fat person to a buffet! I mean first of all I'm – what do you call it – bulimic? So I could eat. [laughs] You know what I mean? And now I'm diabetic. So I mean you want to take me to a buffet? That's just stupid. So I mean I wouldn't stop. I wouldn't say I've got to watch what I'm eating because of my diabetes. I'd just have a nice big pig fest and come home, do my business. By the time I got home from the buffet my sugar was 13 whatever. As soon as I went and did my business, I was back down to a 5 or 6.*

**Food, fear and anxiety.** Certainly not all women reported resorting to unstable or hazardous dietary practices during their pregnancies, however, many expressed feeling powerless as a result of their emotional reactions to food. Elaine's complaints that "*it was hard*" to follow the dietary advice she received because, "*when you're pregnant you have these temptations to eat a lot.*" Faye referred to food as a "*pacifier*", used to alter mood and emotion. Past relationships that women have had with food mixed with prenatal cravings often resulted in seeking out "comfort foods" when under stress. Doris said, "*somebody says something or things aren't going right, you go eat!*" Alice recalled, "*I was going through a lot with school and also some family issues. I think that's what caused my sugars to get up, so sometimes I would sneak in some food that I shouldn't be eating you know, I call it comfort [food].*" Alice seems to have developed this pattern or relationship with food when she was young. She remembered, "*when I was growing up, I always had junk food. I lived on junk food. I'm surprised that I wasn't a diabetic when I*

*was a kid!*” She also associated certain types of foods with happy events in her childhood. Her mother and father were away from home often with work, but when they returned, *“it was like Hallowe’en.”* Those were positive events. According to Alice, *“the candies were my happy thoughts.”*

Strong emotions were also attached to the practice of prenatal food provision, or feeding children, with feelings heightened when diabetes or the threat of future diabetes are factored in. Doris worried, *“when my sugar was high I always thought, did I give her too much sugar ‘cause she’s moving around a lot and you wonder, ‘did I eat too much fruit?’”* Four other women were so concerned about the health of their babies that they limited their food intakes towards the end of their pregnancies in an effort to stabilize BG levels. Lena remembered during labour with her sixth child her doctor was concerned about her low blood sugar because as she explained during her final trimester, *“no matter what I eat, it’ll skyrocket. So after a while, it just seemed easier just to drink [than eat].”* Alice remembered she had been told by her doctor during her last pregnancy that if she did not control her BG her baby would be stillborn. She recalled, *“that scared me! That stressed me out! In that two weeks I watched what I ate. Sometimes I didn’t eat at all. I would live on water.”*

Alice who had been diagnosed postnatally with type 2 diabetes at the time of her interview discussed the management of GDM during her previous pregnancies as stressful because of the added pressure and responsibility of her unborn child’s health. Alice explained that once her baby was born she did not have to worry about what she ate because, *“I’m not pregnant and I’m not going to hurt anybody inside me.”* Postpartum,

several mothers felt they had more control over their bodies and therefore more freedom to eat without restriction. Carole explained, *“when I’m not pregnant, I could move around a lot more. I could do a lot more. I can control it more myself. But being pregnant with it, it’s hard to control it because the baby’s also bringing the sugar on me. So when you’re not pregnant and you’re diabetic, you could easily control it yourself because you don’t have to worry about feeding anybody else but yourself.”*

Women who experienced GDM had additional worries postpartum. Several participants were fearful that they may develop GDM again or type 2 diabetes. Amber vowed not to go back to the way she was eating before because, *“I don’t want to get diabetes again!”* Participants were also concerned their children may develop diabetes. Darlene, a single mother and victim of domestic violence, struggled to make difficult choices to provide for her three daughters. She seemed anxious about their health and the foods they consumed. She recalled how when she was growing up, she was often forced to eat, and said, *“I’m not going to force my kids to eat what they don’t like. If they’re not hungry why force them?”* She also explained: *“I watch my girls’ sugars and make them eat, drink water more to kill the sugars.”* Since Darlene subsequently developed type 2 diabetes, she went on to explain her motivation for monitoring her daughters’ intakes and the sacrifices she makes out of her worry for their health and well-being: *“I’m doing it for my kids not for myself. I eat the stuff before they eat it so they don’t have the sugar. Like if there is a chocolate bar there I eat it so they don’t eat it.”* Stacey also made some extreme changes based on the fear she felt for her children: *“I got rid of all the food I had – everything like sugar, cereal – everything. And I went and got everything sugar-free,*

*bought fake sugar. I didn't want my kids to end up getting it 'cause they said my kids will get it if I have it, if I don't change their diet. So obviously, I'm going to get rid of all their sugar."*

***Misinterpretation and frustration.*** Women do not want to be criticized for their personal food choice or judged as being lazy or irresponsible. Several participants protested in anger and stated that it "*wasn't fair*" they developed GDM compared to other women they knew based on their personal observations of eating habits. Pam said, "*I'm the only one that had the gestational diabetes out of my sisters. There are three of us and they all eat unhealthy. Like they'll have pop and Slurpees, eat pies. I eat healthy and I'm the big one.*" Lori spoke similarly and compared herself to her cousin who is "*slim, but she eats and eats.*" Her cousin is also pregnant and ironically has not developed GDM even though "*she is eating chips and all this junk and Pepsi.*" Diane blamed those around her and her metabolism, not her diet, for developing diabetes. Although she constantly refers to herself as a "*fat person*" there are factors other than the quantity or quality of the food she consumes to hold responsible: "*my sister, who's my size, goes to McDonald's. She orders a super-sized Big Mac combo, an extra Big Mac and an apple pie. When I go to McDonald's, honest to God, I'll buy myself a double cheeseburger value meal for \$3.99 and I eat the cheeseburger. It's a far cry from – I mean that would be what a skinny person would eat!*"

Adding to the confusion and frustration over the dietary management of GDM are the different perceptions or understandings Aboriginal women have when it comes to food, pregnancy and health. Many women expressed their bewilderment over

contradictory dietary messages. A paradoxical statement Diane made illustrates that nutrition education is not necessarily clear or meaningful to Aboriginal women. She said, *“just because it’s healthy for me doesn’t mean it’s good for me.”* Diane distinguished the phrase eating healthy as different from *“eating healthy diabetic.”* She elaborated further: *“when you think of healthy you think of fruit and vegetables, but tomatoes and apples and oranges and whatever aren’t good for you, they’re high in sugar.”* At the same time she explained that for women with GDM, *“chocolate bars aren’t bad for you, because chocolate doesn’t release its sugars all at once like Pepsi.”* Sharon made a comparable description of her confusion over nutrition messages she had received: *“I’d eat like an apple, and my sugar would go up and up. Well, why can’t I eat an apple? Like I just...I didn’t understand. And then you were thinking ‘okay, well if this is all you can eat, how’s your baby getting the nutrition that it needs to grow?’”*

Faye suggested that Aboriginal mothers may not be aware of the nutritional values of foods they are eating or told to eat when they have GDM and explained, *“we don’t grow up in a household and talk about carrots having beta carotene, you know.”* Another participant confirmed her lack of formal knowledge resulting in a complete lack of trust of the nutrition education messages she was receiving from her health care providers. Stacey recalled, *“they told me I’m supposed to be on this crazy diet where there’s only lettuce and vegetables and they put me on this diet that made my blood go up to like 20. And I told them, ‘I’m not going to go on that diet because the diet you guys put me on – the way you’re talking, you guys are killing me quicker than before I was eating my fries!’”*

Other women had difficulty following the advice they received from dietitians and other health care providers. They expressed anger and outrage and rejected counseling messages as Stacey did, preferring instead to respond to bodily cues and the experiences of other women they trusted. Doris, for example, was cautioned by her doctor about excessive weight gain during her first pregnancy. Until that time she wasn't worried, *"because my sisters all gained weight – lots of weight and lost it after. And they told me, 'just eat, eat, eat, 'cause you're going to need it.'"* Marion also listened to her cousin's advice when she was pregnant with GDM because her cousin had experienced the same body cues with low BG and was worried: *"I feel like I can't even get up'. She's like, 'you need to eat something. You know what that is; that's your sugar'."* Deb was also aware of her body and rejected her healthcare provider's advice to cut down on the quantity of food she was eating while pregnant. She firmly stated, *"it wasn't only me that was hungry. It was the baby that was. My baby was hungry, and I'm going to eat!"*

Aboriginal women who have grown up in their communities around extended family indicated trust of their bodily cues and family advice around food. As a first time mother at the age of 18, Tina had learned to trust her body and family members to guide her through her pregnancy and make good decisions about food choice. She was eating more meat, *"because I have to now, not only for my sake, for the protein and my Auntie was telling [me], 'eat as much wild meat as you can.' So my two sisters were hunting almost right through the whole winter."* Sharon grew up in a rural Métis community and also described the supportive advice she received from family members, and the knowledge that it is difficult to change handed down traditions:



*Nutrition wasn't a big thing though when I was growing up. Like being set on, 'this is your veggies, and you got to eat all this, and you got to eat that'. Your mom and your grandma made you your food, and that's what you ate, and you're supposed to eat because they knew best, right? So I think that's the way that I look at it, because I'm the same way. I don't think that I could follow a guide or something to tell me what I can and can't feed my kids. I think we're evolving right? More people are being educated; more people are being aware of what they're doing, and for us it takes a longer time because we have the old ways people do it, and then our families are so ingrained in each other in the Aboriginal community that it's like a circle. They have their own ways of doing things, and it kind of gets handed down to us, and it's hard to change.*

## **Discussion**

For this group of Aboriginal women with gestational diabetes, factors influencing food choice and eating behaviours are multifaceted. Participants in this study were both attempting to gain control of their challenging life situations as well as their BG levels in managing GDM. Many existed in dysfunctional or even abusive environments with a myriad of stresses such as economic or social pressures that influenced their ability to react confidently to treatment advice and effectively control their GDM. The emotional responses women described during their interviews, such as fear, anxiety, frustration and anger were often interconnected and seemed to result in unhealthy behaviours or negatively influence thoughts about food, including the unstable prenatal eating practices of several participants. These circumstances also have the potential to negatively influence women's abilities to adjust dietary and other treatment prescriptions through individual food selection practices.

When faced with stressors that are perceived as difficult to manage there is also the increased likelihood of using emotion-focused coping strategies to limit feelings of distress even if the stressor itself cannot be eliminated (Greenfield and Marks, 2009).

Once diagnosed with GDM, women in this study appear to have little control or choice over factors that are viewed as contributing to their condition, yet it is often perceived as an individual's choice to eat a certain way or live a particular lifestyle. However, as Thompson and colleagues (2000) point out, people with less control over what they eat are more likely to eat irregularly and whatever is most convenient or appealing. Similar practices were mentioned by participants in this study. They spoke of difficulties adjusting the types of foods normally consumed and preparing smaller meals more frequently. Non-Aboriginal women coping with GDM were found to exhibit emotional responses, such as anger and frustration when advised to alter long-standing eating habits (Lawson and Rajaram, 1994). Vallianatos and colleagues (2006 and 2008) also reported pregnant Cree women had difficulty breaking established, although irregular, eating patterns and would seek out fried foods and sodas often out of boredom. In southern Manitoba, Saulteaux women commonly mentioned craving "junk foods" during pregnancy (Neufeld, 2003). A recent analysis of Aboriginal women's eating patterns living off-reserve in Canada also supports these findings (Garriguet's 2008). For women aged 19-30 their average daily intake exceeded non-Aboriginal women by 359 calories, which mainly consisted of snack foods and soft drinks. Close to 36% of their daily caloric intake took place irregularly outside of established meal-time schedules.

Adams (2003) has indicated that when women are diagnosed with diabetes it can lead to a preoccupation with food. These tendencies were described by several of the participants in this study. Women reported inconsistent meal patterns and erratic quality and quantities of foods. Prescribed "healthy" foods such as fruits and vegetables and milk

products were not viewed as appealing compared to fried foods. Comparable food patterns have been previously described by urban American Indian women in Minneapolis. Fruits or vegetables were not consumed on a daily basis compared to high fat foods, mainly due to taste preferences. Other barriers to consuming a lower fat diet included food availability, time constraints and lack of food preparation skills (Harnack et al., 1999).

Two women in this study confided that they would engage in secretive practices such as binge eating and vomiting to manage their weight and blood glucose levels, although several other women discussed regularly overeating (see Table 6.4). Most of the literature on unhealthful eating practices among other Aboriginal populations in North America has focused on weight issues among adolescent girls (Neumark-Sztainer et al., 1997; Snow and Harris, 1989; Story et al., 1994 and 1995;). Few have included Aboriginal women (Harnack, 1999; Marchessault 2001 and 2003; Rosen et al. 1988). Marchessault (2003) found Aboriginal women living on and off-reserve in Manitoba were more preoccupied with weight issues compared to non-Aboriginal women. Aboriginal girls were more at risk of developing an eating disorder (17.5%) compared to only 2.5% of Caucasian women, but there appeared to be a general acceptance or normalization of practices such as vomiting as a method of weight control, with 40% of girls living on-reserve admitting they viewed vomiting as a viable way to maintain or lose weight (Marchessault, 2001). An even higher percentage of Aboriginal women and girls described dangerous weight loss techniques in northern Michigan with 75% of females aged 12-55 resorting to potentially hazardous methods to lose weight (Rosen et al., 1988).

Close to one quarter of the women used purging behaviours such as vomiting, laxatives and diuretics. Although girls were found to be more prone to developing an eating disorder, women with higher BMIs were more likely to use these pathogenic weight-loss methods.

The concept of distress is commonly associated with diabetes and its complications. Disturbingly high rates of depression, anxiety as well as eating disorders have been reported (Rock, 2003). The demands of day-to-day diabetes management may also increase perceived stress, resulting in a higher risk for these psychological disorders (Rubin and Peyrot, 2001). As some of the participants in this study discussed, when the pressures of dealing with GDM become unbearable, food was used to self-soothe. Particularly in the case of depression, food may be used as a source of comfort (Rubin and Peyrot, 2001). Incidences of disordered eating practices for pregnant women with type 2 diabetes or GDM have yet to be reported in the published literature. Eating disorders for those with type 1 diabetes have been described, particularly among young Caucasian women in response to dietary restraint and the initiation of insulin therapy which may cause weight gain (Hillege et al., 2008; Krenz et al., 1993). Insulin manipulation as a means of weight loss has been identified as well as practices such as binge eating and purging (Jones et al., 2000; Rodin et al., 2002; Rydall et al., 1997). Fewer references exist for non-pregnant individuals with type 2 diabetes. A German study found no difference in the prevalence of eating disorders between type 1 and type 2 patients. There did appear to be differences in distribution, with binge-eating disorders more common among type 2 diabetes patients (Herpertz et al., 1998). Among Australian

women with type 2 diabetes, 21% reported regularly binge-eating. The practice was significantly associated with poorer well-being, earlier age of diagnosis, lessened self-efficacy for lifestyle management and higher BMI (Kenardy et al., 2001). Among those studies published on eating patterns for Aboriginal populations with type 2 diabetes, there are few that describe dangerous or unstable eating practices. A study among Aboriginal Canadians with type 2 diabetes living in an urban centre in southern Ontario, however, briefly described the concept of food addiction for diabetics with both diabetes and alcohol viewed as problems of addiction. Aboriginal men and women with type 2 diabetes would hoard large amounts of candy to eat in secrecy (Hagey, 1984).

Anxiety associated with food insecurity has been previously described for non-diabetic Aboriginal women (Willows et al., 2008), although interestingly given the economic circumstances reported, there was little discussion about issues of food access or food insecurity in this study. Pregnancy itself has, however, been reported to be a source of stress for Aboriginal women who are classified as “socially high risk.” Many worry about pregnancy outcome, in addition to other life stressors such as money (Bowen et al., 2008). Participants in this study who were also dealing with GDM similarly worried about the health of their babies. This anxiety is particularly acute for women who had previously lost a child, as was the case for several participants in this study. Poudrier and Kennedy (2008) found that Aboriginal women living on-reserve in Saskatchewan were scared to eat because of upcoming diagnostic tests for diabetes. Among the group in Winnipeg, several similarly refrained from eating during their final trimester to try and control BG levels. The anxiety women in this study felt around food when it came to their

children's health certainly added to the myriad of negative circumstances in their lives. They wanted what was best for their children and were willing to sacrifice their own health. In a previous study, Aboriginal women living on-reserve in Manitoba also talked about protecting their children's health as a result of the fear and concern they had for pregnant women and their babies in their community. Mothers were careful about their sugar consumption because of the strong presence of type 2 diabetes in their family and community (Neufeld and Marchessault, 2006).

Women in this study expressed a lack of clarity and understanding while receiving dietary counseling for the treatment of GDM. Few had formal teaching on this subject in the home growing up and did not encounter the same messages in their day to day life or through prior schooling. As a result, participants felt they misunderstood nutrition advice and expressed confusion and frustration following nutrition counseling sessions. Lawson and Rajaram (1994) described similar issues for non-Aboriginal women with GDM who must quickly absorb health information, often during the last trimester of pregnancy. They noted that for the majority of women the prescribed diet "posed multiple difficulties and challenges" (p. 549). Other women expressed doubts about the reality of their condition in reaction to those around them who were eating excessively and yet did not develop GDM. These inconsistencies in explanations for the development of type 2 diabetes were similarly expressed by Aboriginal men and women living on-reserve in Manitoba. Discrepancies in eating behaviours not leading to a diagnosis of type 2 diabetes were personally observed and caused frustration (Garro, 1995).

Certainly a complex and unique set of influences on food practices exist for

Aboriginal groups. As Omura has suggested, food choice and eating practices can be heavily influenced by social relationships and cultural membership (Omura, 2006). The symbolism of food and the trust that exists between the individual and their larger community has been described by several authors (Delormier et al., 2009; Garro, 1995; Lang, 1985; Smith-Morris, 2006; Sunday et al., 2000). The complexity of food habits was expressed by Sharon, a Métis woman, who pointed out in the final quote that there are those in her community who live between cultures and are perhaps more tied to traditions. Thompson and colleagues (2000) have written about the sociocultural context of food. Based on their research among Aboriginal groups in Australia, they have similarly found that food serves as a strong symbolic social resource to link family relationships in the present and past. The practice of redefining foods such as lard and bannock that are generally categorized as “unhealthy” by the medical establishment, risks disrupting people and relationships from the past, although it may improve the health of future generations. Frustration and the rejection of care and nutrition counseling may also signal a lack of connection between messages delivered and the worldview of a mother with GDM. As Deb indicated she listened to her body and baby’s hunger instead of the advice of her dietitian to reduce the quantity of food she consumed. Clarke (1990) has reported similar practices for pregnant Coast Salish women in British Columbia. Women listened to their bodies during pregnancy to learn what was harmful or beneficial to their baby’s health.

Core values such as food environment, motherhood and identity or ethnicity are associated with gestational diabetes. It is no wonder, as Smith-Morris (2006) suggests

that Aboriginal women feel threatened on symbolic and political levels. There are so many dimensions that are beyond their control. If nutrition education can be framed in a culturally acceptable way with more control and therefore personal autonomy or safety factored in, women can make decisions for themselves based on greater understanding and confidence. Aboriginal women with GDM need the emotional support and spiritual strength to regain control and balance to make food choices that are appropriate for them.

Rubin and Peyrot (2001) point to the need for in-depth counseling and support for individuals with diabetes as well as an increased focus on emotional outcomes, especially around eating. GDM represents both the “burden of a potentially chronic, life-threatening illness” combined with the psychosocial stress of pregnancy (Lawson and Rajaram, 1994; p.557). Further attention should therefore be directed towards the psychosocial management of GDM with emphasis on flexibility, balance and personal preferences when it comes to food choice. Avoiding an unhealthy focus on “forbidden foods” could lead to decreased feelings of guilt and deprivation. Resolving these emotional issues in living with diabetes would also provide broad benefits since decreased levels of distress are associated with more active diabetes self-care (Rubin and Peyrot, 2001). If pregnant women also get more pleasure from eating in spite of their GDM, these perhaps new behavioural patterns in cooperative contexts will be associated with positive social meaning (Thompson et al., 2000) and lessen feelings of anxiety, guilt and frustration that potentially negatively influence women’s self esteem and sense of control over their lives and GDM.

The results reported here point to the need for a more in-depth understanding of



the complexity of eating behaviours and food perceptions for Aboriginal women with gestational diabetes. Women in this study described eating habits that are not only unhealthy for mother and child, but could be dangerous if past food practices continue during pregnancy. There are also the risks of excessive weight gain with unstable and binge-eating practices that could negatively contribute towards the perpetuation of the cyclical pattern of diabetes and its transference to the child (Dabelea et al., 2000). Given the increasing rates of GDM in the Aboriginal community (Garriguet, 2008; Brennand et al., 2005) and the rising percentage of Aboriginal women and children living off-reserve (Statistics Canada, 2006) there is the need to focus efforts on the improved management and prevention of GDM in urban areas. However, a better understanding is critical for a more targeted intervention to promote healthy eating practices both prenatally and postpartum to prevent against the future development of type 2 diabetes for mother and child (Feig et al., 2008; Vallianatos al., 2008). There is legitimate concern that interventions are necessary to prevent pregravid obesity and excessive weight gain in pregnancy for Aboriginal women to reduce rates of GDM and prevent its potential poor maternal/fetal outcomes (HAPO, 2009); however, given the results of this investigation, factors influencing maternal dietary behaviours when combined with GDM dietary restrictions are complicated. The range of influences on food choice must be considered.

It is difficult to generalize these findings to the larger community of Aboriginal women in Winnipeg or other Canadian urban centres because of the size of the sample and method of recruitment. The volunteer sample of participants was also achieved through advertisements and presentations in clinical as well as community settings. The

majority of women who responded were already accessing health care services in Winnipeg; however, four were First Nation women who were living outside of the city on-reserve. Nonetheless, a qualitative investigation of how Aboriginal women with GDM perceive food is a topic that has yet to be reported in the literature. There have been other qualitative investigations that examined prenatal food choice and diabetes during pregnancy in Aboriginal communities (Neufeld, 2003; Smith-Morris, 2006), but neither of these studies looked specifically at GDM or were conducted in an urban setting. Further in-depth research is required on the meanings of food patterns and behaviours to Aboriginal women with GDM, especially those women who are removed from their home communities and potentially most isolated. Rates of GDM are only continuing to rise among all populations of women (Hunt and Schuller, 2007; Vibeke et al., 2008). There is a critical need for understanding and appropriate action in the form of prevention, particularly for those women and their children most in need of attention.

Table 5.1. Sample of explanatory model interview questions

<b>Illness Category</b>	<b>Sample Questions</b>
Etiology	Do you think more women are getting gestational diabetes today than in the past? Why or why not?
Pathophysiology	If you had to explain to someone how gestational diabetes works, how would you describe what happens inside your body?
Onset	Can you tell me about how you found out you had gestational diabetes? When did it happen?
Course	Do you ever think that you will have diabetes again?
Treatment	How do you think diabetes during pregnancy should be treated?
Prevention	What do you think a woman can do so she won't get gestational diabetes?

Table 5.2: Participant pseudonyms, diabetes and obstetric description at time of interview

Pseudonym	Diabetes and Prenatal Status	Children <sup>a</sup>	Residence
Darlene	GDM with last pregnancy, three years ago	3	Winnipeg
Tracy*	GDM with previous pregnancy, 7 months ago; first trimester	10	Winnipeg
Alice	Currently type 2 after 4 <sup>th</sup> pregnancy with GDM, 4 years ago	5	Winnipeg
Marion	Currently type 2 after 4 <sup>th</sup> pregnancy with GDM, 1 year ago	4	Winnipeg
Sharon	GDM with first pregnancy 1 year ago	1	Rural MB
Pam	GDM with first pregnancy 4 years ago	2	Winnipeg
Dawn*	GDM currently; first trimester	1	Winnipeg
Deb	GDM with previous 2 pregnancies, 1 and 2 years ago	5	Winnipeg
Carole*	Currently has type 2 after 3 <sup>rd</sup> pregnancy with GDM, 2 years ago; 2 <sup>nd</sup> trimester	3	Reserve
Terri*	GDM with prior pregnancies and currently; 2 <sup>nd</sup> trimester	3	Winnipeg
Eva	GDM with last pregnancy, 2 years ago	3	Winnipeg
Anita	GDM with last pregnancy, 3 years ago	4	Winnipeg
Nancy	GDM with first pregnancy, 3 years ago	2	Winnipeg
Sandy*	Currently type 2; GDM with last 2 pregnancies, 1 and 2 years ago; 2 <sup>nd</sup> trimester	3	Winnipeg
Tricia	GDM with last pregnancy, 6 months ago	2	Winnipeg

Elaine*	GDM with last pregnancy, 3 years ago	1	Winnipeg
Linda*	GDM currently and with last pregnancy 2 years ago; 3 <sup>rd</sup> trimester	4	Winnipeg
Cindy*	GDM currently; 2 <sup>nd</sup> trimester	2	Reserve
Faye	Currently type 2, GDM with last pregnancy, 2 years ago	3	Winnipeg
Tina*	GDM currently; 2 <sup>nd</sup> trimester	0	Reserve
Lori*	GDM currently and with last pregnancy, 11 years ago; 3 <sup>rd</sup> trimester	1	Winnipeg
Amber	GDM with last pregnancy, 3 months ago	1	Winnipeg
Lorna*	GDM with current pregnancy; 3 <sup>rd</sup> trimester	2	Winnipeg
Doris*	GDM currently; 3 <sup>rd</sup> trimester	0	Winnipeg
Stacey*	Currently type 2, GDM with last 2 pregnancies, 2 and 4 years ago; 2 <sup>nd</sup> trimester	4	Winnipeg
Veronica*	GDM currently; 3 <sup>rd</sup> trimester	1	Winnipeg
Claire*	Currently type 2; GDM with last 2 pregnancies, 1 and 3 years ago; 2 <sup>nd</sup> trimester	2	Reserve
Lena	GDM with last 2 pregnancies, 3 years and 5 months ago	7	Winnipeg
Diane*	GDM with current and last pregnancy, 3 years ago; 2 <sup>nd</sup> trimester	4	Winnipeg

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<sup>a</sup> Given birth to, not necessarily currently living with

\* Participant pregnant at time of interview

Table 5.3. Demographic characteristics of participants

Characteristic	Aboriginal women (n=29)
Median Age (years) (range)	30 (18-43)
Education Level (# of women)	
Up to high school	11
High school and Post-secondary	17
Some post-secondary	11
Completed post-secondary	1
Median # of children (range)	3 (0-10)
Average annual income category (\$) (range)	24,500 (7,500-45,000)
Family background (# of women)	
Saulteaux or Ojibwe	12
Cree	9
Métis	4
Oji-Cree	2
Unknown*	2

\* Women had grown up in foster care and were unaware of their heritage.

Table 5.4. Summary of eating behaviour themes compared to pregnancy, prescribed diabetes treatment and residence status at the time of the interview

THEME	Pregnant n=16	Not Pregnant n=13	Insulin n=18	Diet n=11	On Reserve n=4	Off Reserve n=25
Preferences	16	10	16	10	4	22
Fear/Anxiety	14	11	16	9	4	21
Instability	13	11	14	10	2	22
Misinterpretation	13	10	14	9	3	20
Poor Quality	12	9	12	9	2	19
Overeating	9	8	9	8	1	16

**Chapter Six**  
**Perspectives of Health Provision Practices for**  
**Aboriginal Women with Gestational Diabetes**  
**Accessing Services in Winnipeg, Manitoba**

The *Report of the Royal Commission on Aboriginal Peoples* chronicled the lasting influence of past discriminatory policies on the lives of Aboriginal<sup>1</sup> peoples in Canada. One of its main recommendations was a call for justice and equality for all Canadians (RCAP, 1996). Over a decade later, major discrepancies continue to exist in health status and health services access between Aboriginal and non-Aboriginal groups in Canada (AFN, 2006; Macaulay, 2009). Life expectancies for Aboriginal men and women are five to ten years lower than the Canadian averages and rates of chronic diseases such as heart disease and type 2 diabetes are significantly higher, with the prevalence of type 2 diabetes three to five times higher than the general population (CDA, 2008; Health Canada, 2000).

Aboriginal women appear to be at significant disadvantage according to these health status measures with elevated rates of injury, suicide, obesity and diabetes relative to other Canadian women (Dion Stout et al., 2001; Dyck et al., 2010). Rates of gestational diabetes mellitus (GDM) are also higher among Aboriginal women than the non-Aboriginal population (Ishak and Petocz, 2003; LaVallie et al., 2003; Rodrigues et al., 1999). According to the current *Canadian Diabetes Association Clinical Practice Guidelines*, Aboriginal women are at “more than twice the risk” of GDM compared to

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<sup>1</sup> In Canada, “Aboriginal” includes status and non-status First Nation, Inuit and Métis people (Frideres and Gadacz, 2008) and will be used throughout this paper to refer to persons of First Nation and Métis backgrounds collectively.



non-Aboriginal women, and have higher rates of pre-existing type 2 diabetes in pregnancy (2008; p.S187).

Although the need for a better understanding is recognized, studies describing the experiences of pregnant Aboriginal women with the healthcare system are few. Much of the research aimed at trying to reduce these health disparities is focused on the health of Aboriginal Canadians on-reserve, even though higher rates of poverty, obesity and diabetes have been documented off-reserve (Tjjepekema, 2002). The health needs of women and children have also received less research focus proportional to their share of the population living in Canadian cities (Young, 2003). Young Aboriginal women seeking prenatal care in urban settings tend to receive inadequate care. Whether this is a result of lack of resources or perceived barriers to care has yet to be investigated in detail (Heaman et al., 2007; Smith et al., 2005).

Although there has been much discussion in the literature about “culturally appropriate” care for Aboriginal populations and their general dissatisfaction with health care services on and off-reserve (Benoit et al., 2003; Browne and Fiske, 2001; Dion Stout and Downey, 2006; Kurtz et al., 2008), few studies have investigated perceptions of prenatal care, particularly for Aboriginal women accessing care off-reserve. Those women who are classified as having an “at risk” pregnancy, such as the increasing numbers of young women experiencing a pregnancy compromised by diabetes, are especially important to listen to, and understand what barriers they may or may not face in approaching prenatal and endocrine specialists in an often unfamiliar urban setting. Only a handful of previous studies have examined the experiences of Aboriginal women seeking prenatal care (Long and Curry, 1998; Smith-Morris, 2006; Sokoloski, 1995).

None have yet examined health care for Aboriginal women coping with GDM in an urban Canadian context.

Given the lack of formal investigation into this topic, a qualitative investigation was proposed to ask Aboriginal women about their illness experiences with gestational diabetes. The primary objective in conducting this study was to describe how Aboriginal women experience gestational diabetes based on their own explanations of the illness or condition. This paper presents women's perspectives on the prenatal care they received, contrasted with the impressions of agency workers, Elders and health practitioners involved in Aboriginal women's health in the city of Winnipeg, Manitoba.

### **Methodology**

Qualitative research methodology is interpretive and experiential (Morse and Field, 1995). It has the potential to generate rich and detailed information to explore and describe in this case, Aboriginal women's prenatal care experiences. Open-ended processes such as interviewing, are also reciprocal exchanges, characterised by a more equitable balance of power with minimum control on the part of the researcher (Smith, 1999). Participants are free to express themselves and their experiences in their own terms and at their own pace (Bernard, 2002; Sunday et al., 2001). Dialogue collected through in-depth interviews has the potential to give "insight into the assumptions that your participants use to understand their world of experience, the components of that world, and how those components are organized to form social and behavioural ecosystems"(Handwerker, 2001; p.107).

The primary method of data collection for the study was therefore interviewing. Open-ended unstructured interviews or informal focus groups took place with individual

advisors<sup>2</sup> or groups of advisors, to provide context for the semi-structured questions and overall research process. These unstructured discussions generally explored issues and impacts of the health care system and other external support systems impacting prenatal care services for Aboriginal women in Winnipeg. For example, health professionals were asked, “how do you think gestational diabetes affects Aboriginal women?” Aboriginal community leaders and advocates were also invited to discuss the availability of community support and resources for pregnant Aboriginal women in the city.

The second series of interviews took place with a group of Aboriginal women participants who either currently had GDM or had been diagnosed within the past five years. These semi-structured interviews began and ended with background questions to obtain demographic information to describe the sample. As a theoretical orientation to guide the semi-structured interviews, Arthur Kleinman’s Explanatory Model Framework was used to conceptualize and understand Aboriginal women’s experiences with gestational diabetes (Kleinman, 1978). Although the study was designed to describe Aboriginal women’s experiences with GDM, women talked extensively about their interactions with health care advisors as they answered the series of questions framed around the nature of their illness experience. The semi-structured interviews included a series of open-ended questions framed around five themes: onset, etiology, course of illness, treatment, and pathophysiology. The theme of prevention was added as a sixth theme to explore, given a previous lack of investigation into this area. Sample questions can be found in Table 6.1. The interviews with Aboriginal women also contained a fixed response interview to assess cultural consensus however, these results are reported

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<sup>2</sup> Use of the term “advisor” is used throughout this paper to replace the more common term of “key informant”, which according to numerous authors can be viewed negatively (Smith, 1999; Oakley, 1981).

elsewhere (Chapter 4). Quotes have been edited slightly to improve readability while not altering meaning (Neufeld et al., 2006). Pseudonyms are used for the participants and advisors to preserve anonymity.

**Research process.** Letters of introduction were initially sent to list of 12 potential advisors knowledgeable in the area of Aboriginal women's health to request their input and volunteer participation in the study. It was left up to the discretion of the individual or organization contacted whether one person chose to be interviewed or a group of advisors to form a focus group. Through these contacts, further support and participation from central and northend clinics, hospitals and local health and social service agencies were established and assisted in the recruitment of participants.

Self-declared Aboriginal women who had been diagnosed with gestational diabetes during their current pregnancy or within the past five years were recruited for the research project. Women responded to posters displayed in various health care locations around the city. They were also given contact information by friends and health care providers. Informal presentations on the topic of GDM were also made by the author to various community and prenatal women's groups to establish contact with potential participants. The author also regularly attended local antenatal and diabetes education clinics where women who fit the inclusion criteria were asked privately by nursing staff if they wished to participate, prior to being introduced to the author to arrange a time to be interviewed.

Recruitment of participants and advisors took place from November 2006 until September 2007. Prior to data collection, ethical approval for the study was received from the University of Manitoba Health Research Ethics Board, the Health Sciences

Centre Research Impact Committee, Health Canada Research Ethics Board, and the Winnipeg Regional Health Authority Research Review Committee. All of the interviews and focus groups were conducted exclusively by the author once informed consent had been established with both the advisors and participants.

**Analysis.** Interviews and focus groups were audio-taped and transcribed verbatim. During the interviewing process, field notes were also kept. Transcripts were reviewed and corrected against the original audio files and an initial list of themes was incorporated into the project in NVivo7 (Qualitative Solutions and Research, 2006), along with field notes. Transcripts from both the advisors and participants were read, searched and coded into categories and eventually themes using a method of constant comparison (Lincoln and Guba, 1985). The process also involved connecting themes and modeling relationships by making memos to support the rationale and sequential process of the analysis (Richards, 2005). Themes and categories were further analyzed through matrix coding queries that assisted in identifying categorizing relationships by linking with participant characteristics or attributes with previously coded dialogue (Bazeley, 2007).

**Participant description.** Ten advisor groups were recruited for the study. Four focus groups and six interviews were conducted with 25 individual advisors (see Table 6.2). The focus groups mainly took place with health care professionals working in both clinical and community settings. One-on-one interviews occurred with two health care practitioners, two community advocates, one government employee and a female Elder. Interviews and focus groups mainly took place at the advisors' place of employment and averaged 54 minutes. One community activist preferred to be interviewed at home.

Advisors were purposively sampled based on their profession and extent of involvement with Aboriginal women in the city of Winnipeg. Five advisors were First Nation or Métis women themselves.

Close to 44% of Aboriginal women participants preferred to be interviewed in their homes or outside of a clinical setting. Eight of the thirty interviews took place at a hospital or clinic. The remainder chose to meet at local coffee shops or restaurants. Women were usually interviewed once with the interview lasting an average of 69 minutes. One participant was, however, interviewed in four parts. Her total interview time was two hours and 43 minutes. Thirty Aboriginal women participated in the study. Women ranged in age from 18 to 43 years of age. On average they had three children (range 0-10) and 16 were pregnant at the time of the interview. Eighteen or 62% of participants in this study were prescribed insulin to manage their GDM. Nine women had GDM at the time of their interview, while 11 had experienced it previously, and at least nine subsequently developed type 2 diabetes. A woman from a northern reserve community was excluded from analysis because it was later determined she had been diagnosed with type 2 diabetes when she was nine years old, which brought the total sample size to 29. It was also determined that over 60% of the women's own mothers had type 2 diabetes and 30% of participants grew up in the city. Close to half of the women had moved to Winnipeg as adults to work or attend school. Only four women were living on-reserve at the time of the interview, but travelling to Winnipeg for healthcare. Twelve women self-identified as Saulteaux or Ojibwe. Nine women identified as Cree, two as Oji-Cree and four as Métis. Two others were unaware of their Aboriginal background since they had grown up in foster care. Additional background detail for both participants

and advisors appears in Table 6.3. Tables 6.4 and 6.5 include a complete listing of pseudonyms for advisors and participants with some added description.

**Ethical considerations.** The study was approved by the University of Manitoba Health Research Ethics Board, the Health Sciences Centre Research Impact Committee, Health Canada Research Ethics Board, and the Winnipeg Regional Health Authority Research Review Committee. An effort was made to adhere to the *Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007).

## **Results**

There were two main categories that arose from the interviews and focus groups on the topic of health service provision. Both participants and advisors talked about barriers they felt limited access and quality of prenatal care as well as diabetes education. They also discussed aspects of patient and caregiver communication that may compromise the delivery of prenatal care to Aboriginal women with GDM. A summary of the main thematic topics according to occupation and self-reported identity for advisors and participants is included in Table 6.6. The following section includes interview content from Aboriginal women participants and advisors beginning with additional background information and context for the thematic discussion to follow.

**Health care context for Aboriginal women with GDM.** In Canada it is recommended that all pregnant women be screened for GDM. For most, screening takes place between 24 and 28 weeks gestation. For those with multiple risk factors, screening is suggested to occur during the first trimester. Risk factors include a prior GDM diagnosis, delivery of a macrosomatic infant, age greater than 35 years, or an elevated

pre-pregnancy weight or BMI. Those with polycystic ovary syndrome (PCOS), acanthosis nigricans, and members of certain population groups, such as Aboriginal, African, Asian or Latin American women are also categorized as higher risk (CDA, 2008). For Aboriginal women in Winnipeg this initial screening usually takes place with a general practitioner, obstetrician or midwife. If women are new to Winnipeg or do not have an established family doctor, prenatal services that include the screening and diagnosis of GDM are generally provided through several clinics. Two are located within the largest hospitals in the city: St. Boniface Hospital and the Health Sciences Centre/ Women's Hospital. In addition to ambulatory services, both of these institutions house diabetes education centres.

Aboriginal women who are diagnosed with GDM following screening are primarily referred to one of the education centres to discuss management plans with a diabetes nurse and nutrition with a dietitian. A visit with an endocrinologist is scheduled. Those who are travelling into the city from nearby reserves for prenatal care commonly access services provided at the Health Sciences Centre. Women from more remote First Nation communities generally attend prenatal and endocrine clinics based out of St. Boniface Hospital. Some of these women also await delivery at federally funded boarding homes located across the city. Smaller community health clinics and centres in Winnipeg also provide education to Aboriginal women with GDM who are mainly living in the city. Often these same prenatal nurses, dietitians and diabetes educators regularly attend informal community prenatal groups and deliver group presentations on various topics including GDM. Dietitians and nurses also provide individual counselling at these



community sites as well as provide additional resources and health services referrals as necessary at no additional cost.

During their first visit with a nurse or diabetes educator, women are usually given further information on GDM and shown how to self-monitor their blood glucose (BG) levels. Both preprandial and postprandial testing are recommended by the Canadian Diabetes Association (CDA), to achieve recommended glycemic targets (CDA, 2008). Blood or urinary ketones may also be monitored to assess the adequacy of dietary intake. In addition, it is suggested that women be evaluated and followed by a registered dietitian to ensure that nutrition therapy promotes appropriate maternal weight gain and adequate nutritional intake according to Canada's Food Guide while maintaining euglycemia (Anderson et al., 2006; CDA, 2008). Physical activity should also be encouraged and individualized according to obstetric risk (Anderson et al., 2006). If glycemic targets are not achieved within two weeks from the initiation of nutrition therapy, it is recommended that insulin be initiated. Multiple injections and monitoring of BG are necessary to maintain appropriate BG values and insulin continuously adjusted (CDA, 2008). This process necessitates regular appointments with an endocrinologist and a diabetes nurse educator to monitor records and regulate insulin as required. Other pharmacologic treatments, such as the use of glyburide and metformin to control BG, are not approved for pregnant women in Canada (CDA, 2008).

Women who have had GDM should be encouraged to breastfeed to reduce the potential development of childhood obesity or type 2 diabetes, especially Aboriginal families who are at higher risk (Dabelea, 2007). Postpartum testing and screening is also advised to identify women who continue to have elevated glucose levels as well as to

prevent future development of type 2 diabetes. These preventive measures, in addition to CDA's further recommendation for pre-conceptual screening for type 2 diabetes among women with former GDM, however, do not consistently occur. Many women do not receive adequate follow-up post-partum (CDA, 2008).

### **Health service divisions**

*I don't know if it's so much access to healthcare because I think in Winnipeg there would be access, but again it's more trust of the system that there has been so much reporting done and things. And that they don't want to be identified as people that have problems, right? I mean you're always stigmatized as people that have all these challenges. (Suzanne, prenatal program manager/government employee)*

Prenatal and postnatal barriers to providing care for Aboriginal women with GDM were explored with all of the advisors who participated in this study. Advisors were asked their impressions about health services and the most significant or challenging issues faced by pregnant Aboriginal women in the city. Most began their discussions by describing matters of access and role divisions. For example, Cathy, a dietitian, noted the challenge of providing appropriate education resources for Aboriginal women with GDM. She said, *"I just find some of the stuff is just so wordy and there's not a lot of Aboriginal focus. I was looking and there is basically only one Aboriginal resource [that I use] for diabetes and it is actually outdated."* Participants also provided their own perspectives. When describing their experiences with the health care system, women tended to focus more on their interactions or relationships with providers. Sharon appreciated the extra time health professionals made to help her to understand GDM. She recalled, *"the ultrasound techs were the ones who were informative too like when you asked them questions. So it was interesting 'cause they kind of had a working knowledge of it, and they could explain it to you."* More of these discussions are included in the

sections to follow which include the primary themes that arose from both sets of interviews.

***Burden of responsibility.*** For Aboriginal women with GDM seeking prenatal care in the city of Winnipeg, contradictory education messages when combined with the “*bureaucracy*” of the healthcare system can lead to inconsistent service provision, according to Sharon, one of the participants. Women may not have their own established general practitioner or obstetrician in the city, especially if they are temporary residents or commuting into Winnipeg from nearby reserves. With the exception of the four women living on-reserve, most participants in this study accessed prenatal services from smaller health centres or attended outpatient hospital clinics where according to several women there seemed to be less consistency or support. As Stacey lamented, “*I don’t know what to think but I think that it’s because there’s so many different doctors seeing me, they all tell me something totally different.*” Diane also commented on the time constraints of physicians at the diabetes clinic: “*the doctor really doesn’t give you much time. I mean, I know he’s busy. I know he’s a specialist, but we’re still just going through this.*”

Amber talked about the lack of information when she went to the clinic and would see “*maybe one pamphlet*”. Because she was over 12 pounds when she was born she said, “*I thought I was going to have a really overweight baby.*” Her main source of information on potential outcomes and risks associated with GDM was almost exclusively based on personal experience, resulting in fear and anxiety to discuss her concerns with care providers or family, reflecting a lack of social support. She went on to say, “*it kind of was upsetting because I didn’t know what to expect, because you don’t hear a lot about it. We*

*weren't taught anything about it.*" Doris also complained about a lack of support in the city and suggested there should be *"a lot more people going out and talking about [GDM] – the health reasons."* She went on to say, *"you're kind of shuffled around here. There's some women who come down here [from their reserve], and they don't know anybody."* Although she had attended prenatal drop-in groups herself she found them to be more focused on *"breastfeeding and your child's temperament."* Gestational diabetes was *"just not a topic that you really bring up."*

Several advisors agreed with the participants that there was a lack of time and resources available to respond to Aboriginal women who are in the most need of time and attention to help manage their GDM. Health care providers at a Winnipeg hospital felt constrained for example over budgetary allowances and staffing to support all of the Aboriginal women with GDM who attend their clinic. A nurse, Jane, commented: *"the resources are there, but they're very stretched. In terms of being able to, in an innovative way, create more time and other programs to support people with gestational diabetes. I don't know if support groups or group classes would be beneficial."* She continued to say that the clinic where she worked provided services for gestational patients with a *"very direct link between physician, dietitian and nurse all at one appointment"*, but that perhaps, *"we could improve on that by offering group classes or support groups. I think that that might be something that might be for another area or another organization to provide."*

Heather, a dietitian at the same facility also discussed the possibility of offering group classes to women with GDM. Even though she felt her Aboriginal clients would be more comfortable with *"a sharing circle"* format for *"just a general discussion about*

*gestational diabetes*” that could include time for women’s thoughts and reflections, given the confines of the hospital environment she didn’t think it was a possibility. She felt that she couldn’t “*provide them with the information that could help them or know what this individual is doing.*” Heather also stated that there would be “*more preparation*” with diet histories having to be mailed out and concluded, “*it’s [pause] just not probably something that we can do here. It’s not that we’re not open to change, but I’m trying to, we’re all trying to look at what’s best for the individual.*”

Prenatal program administrators, such as Suzanne, referred to the more flexible environments of pregnancy and parenting groups and similarly commented on the peer group setting that “*makes GDM easier to talk about*”, but went on to say, “*I think it’s just one of those things that it could be done with ‘here’s the brochure.’*” The responsibility of dealing with the prenatal and postnatal challenges of GDM is sometimes diverted to the pregnant patient or local clinics and agencies without sufficient support or explanation. This individualization of care can also extend from the clinical to the community setting. It is often up to women to attend community prenatal meetings for education and support while managing their own blood glucose and lifestyle regimes. Susan, a dietitian, commented that she and her colleagues at a hospital-based diabetes education centre often refer Aboriginal women with GDM to community agencies that specialize in prenatal care, although she was not sure how many patients attended: “*some might phone and others they say they’ll do it. I don’t really know if they ever go or not.*” Even though these organizations potentially offer more flexible support, many tend to focus on “normal” pregnancies as Doris explained, and are not necessarily providing consistent care for women with GDM even though they may be providing social support.

According to Karen, an outreach worker with a community prenatal agency, “*we can give them very simplified education and hands-on ideas.*”

Participants like Amber, however, can come away with the added burden of responsibility when health promotion messages are generalized. She said, “*I think it’s all on us. I think we just have to exercise more and eat healthy. I think that’s all it is.*” Faye also commented that she felt the pressure of accountability when with GDM, but that, “*a lot of it has to do with personal incentive. The educators can only provide you with so much information and education.*” She felt it necessary to be aware of other resources that were available for her during her pregnancy and regularly attended group prenatal programs in the city.

In the community as well as the clinical setting Carolyn, a prenatal health researcher and nurse, recommended that “*everybody [should be] really educated about what to do, that they provide consistent information, and sometimes that’s a problem with these high risk conditions.*” It had been her experience working as a nurse that often women were receiving “*different information about what they should eat and what blood sugar levels they should be aiming for.*” She also noticed that even though there are benefits of having specialists, such as endocrinologists, deal with conditions such as GDM, the entire health care team, “*needs to know what the goals are so they’re giving the same message.*” Unfortunately this may not be a reality for many Aboriginal women receiving care in Winnipeg. Members of the healthcare team sometimes out of frustration with patient compliance, transfer GDM patients out of their care. As Celeste explained to the focus group when asked what would happen if Aboriginal women were struggling to manage their GDM: “*transfer them to OB!*” Her colleague Barb, a diabetes educator then

elaborated: *“that's part of the problem. Obstetrics don't see gestational diabetes as serious either and don't refer them to an endocrinologist. Don't continue sending them somewhere for education. I think that whole message of just the urgency and the seriousness of gestational diabetes and how serious it can be is not out there, with even a lot of the health care providers.”*

This additional displacement or division of responsibility in the clinical setting, combined with patients' confusion as a result of inconsistent messages and attitudes can push women to disconnect themselves from their health care providers and avoid appointments. Some women “fall through the cracks” or perhaps become apathetic about formalized care after a negative encounter. For Aboriginal women who are receiving prenatal care in the city, this situation is especially challenging since many women may also be geographically removed from their home communities and support systems. Like Lori said, *“I was doing it on my own, watching my carbs, doing this and that”,* and thought *“there's no point in seeing her [the dietitian].”* Nancy also explained that, *“once you talk to your doctor, you can do the research by yourself if you're really worried about it – look on the Internet, go to the library and read up about it.”* Sharon found her first nutrition education experiences *“a waste of time.”* She only met with a dietitian twice because her approach, *“rubbed wrong the first time, so I think I didn't want to go back after.”* As a result, she said, *“I did a good job by myself. If the doctor says my sugars are fine then that was good enough for me.”*

Under these circumstances women may be more susceptible to misinformation by isolating themselves, particularly when it comes to managing their diet and insulin injections, which can be dangerous. Faye knew that, *“for anyone not familiar with*

*adjusting the insulin amounts that they've been prescribed, it can wreak havoc.” Her endocrinologist, however, allowed her to adjust her own insulin. As she said, “I didn’t need his permission; I did it on my own. He wasn’t supervising my activity.” Lorna had a similar experience. After receiving mixed messages from a nurse and dietitian about her diet, she was relieved when her obstetrician told her, “you can eat anything you want when you are on insulin, just limit yourself.” She continued, “how my doctor has it, is: I up my insulin when I feel my sugar’s too high. He says, ‘you’re the only one who could tell if your sugars are getting too high. You can up your insulin; just let me know when you up it.’ So my insulin started off at 4. I’m now at 20 units during the day. It’s not bad. He kind of has me doctoring myself.”*

***Assumptions and impacts of blame.*** For Aboriginal women seeking diabetes education, interactions with healthcare providers can also be negatively influenced by a lack of certainty when it comes to causation and risk. A diagnosis of GDM labels the pregnancy as being “at risk.” Issues of lifestyle also factor in. It may be assumed that women who develop GDM are not in control of their weight, level of activity or have poor eating habits. These assumptions may be reflected in the ways Aboriginal women are treated by their health care providers when seeking care for GDM. As Rebecca, a physician from a Winnipeg clinic empathized: *“there’s so much guilt and shame that women have put on them all the time over everything. And I think diabetes is another thing too because it’s not self-induced, but we tell them you have to watch your diet. You have to exercise. And then the women that come back and their sugars are still high. I think they’re worried that we blame them for not caring enough about their pregnancy or baby.”* She went on to recommend that, as health care providers, *“we have to get over*



*that hump and take the guilt away because that's why they don't come back to us. Maybe we lecture more than we listen.”* A former nurse remembered working at a diabetes clinic where she “*did not care for the attitudes of the physicians that worked there.*” Carolyn later described, “*it was kind of a ‘blame the victim approach’. When the women would say, well, she didn’t stick to her diet, well why didn’t she, without any attention to all the various other problems that might be impacting on their ability to follow the diet.*”

Aboriginal women feel these judgements in their interactions with health care providers, even though as Amber stated, “*any woman can get it, it’s just more common in Aboriginal women.*” Participants seeking care for GDM talked about feeling judged or looked down upon by their health care providers. Sharon talked about meetings with a dietitian: “*the way that she was talking about the diabetes, kind of made me feel that it was my fault that I actually had it. Like that I wasn’t watching what I was doing to begin with, and this is how I developed it.*” Darlene commented, “*they had me meet with a dietitian I guess, at the Health Science Centre they had me meet with one. It made me feel like a child because she had her plastic apples and bananas and I was insulted by that. I’m 35 years old you know. Don’t insult me. I know it’s healthy and what’s not.*” Linda described her diabetes education experience similarly: “*I never really got much more than that one day of stuff and I kinda dismissed [it] because of the attitude of the people telling it to me.*”

The explicit blame and judgment of women with GDM in Darlene’s statements reveal were similarly described by Tina, who was living in a reserve community at the time of her interview. She talked about a good friend in the community who had GDM with all of her pregnancies and was asked by a local nurse to talk to prenatal groups about

her experiences. Tina provided this explanation as to why her friend decided not to participate:

*In my community they don't really judge people with it because we know that we could be getting it and we don't know, but now a lot of people are starting to notice that gestational diabetes are not happening to older women; it's happening to younger women now. Like say if my friend went around with the nurse and she could say her side of the story. But I guess she was too shy and too afraid that people would judge her because she had it right through all her babies and she had to take insulin. I think what people would judge her by is that she wasn't eating right and everything, and blame her for it. But it's not only her fault. I think it's just passed down through our parents and they get it from their parents. It just goes from generation to generation, actually.*

How health care providers' frustrations can be misconstrued or perceived as blame or judgment is illustrated by the comments made by Celeste, a midwife, who described one of her Aboriginal patient's lack of compliance: "*she'd come into her appointments with juice cans and if you asked her if she changed her activity, or was eating in the way the diabetes nurse had talked to her: 'well, no not really'. So, I think it's just poor attitude.*" Although her level of caring for her patient and baby is illustrated by Celeste's obvious disappointment and worry, other advisors felt that health care providers may need to work on their level of understanding with Aboriginal prenatal patients. According to Cheryl, an Aboriginal woman working with a prenatal health agency, practitioners must be able to interact with tact, sincerity, compassion and respect. When asked how she felt current programming for pregnant Aboriginal women could be improved, she responded:

*It's all about attitude. A lot of times they'll wear their doctor's hat or their nurse's hat or their professional hat and they use a lot of terminology that [women] can't relate to. A lot of times I think if you come from a low place, you're going to present as timid and shy. And if you're already at that doctor's appointment and you're feeling that way, it's kind of hard to hear what's being said to you. Especially when you've got an attitude where somebody's telling you [that] you have to do this and sometimes that information is presented in a really disrespectful way. And you feel that you're being looked down at.*

*So, I think attitude plays a huge part in terms of the kind of result you're wanting to achieve with the individual.*

### **Patient and caregiver dynamics**

*I always ask myself, 'who are we to judge'? I don't know the pain of that person. Everybody has a story. They might have been traumatized in their childhood. And maybe they'll never get to the place where their life is going to change. So they continue to live their choice. Whatever their choice is, I know that the Creator God understands it. (Violet, Aboriginal Elder)*

**Establishing trust.** The circumstances described in the previous section place Aboriginal women in a position where they feel they are required to navigate within the larger health care system and institutions, practices and circumstances without sufficient or consistent support. This added patient accountability does not necessarily foster trusting or caring relationships between the health professional and patient. For instance, health care providers seemed to struggle with the impact of education messages when it came to the short-term and long-term risks with GDM. Carolyn explained, *"whether we do a good job of teaching it, I don't know. How helpful it is to say that you're going to be more at risk for diabetes in later life? That's just an anxiety producer I think, unless you give women some of the tools and suggestions for what they need to prevent that from happening."* Another advisor, Heather, similarly said *"for the pregnancy you're are in a very fragile state, so you're not going to stress these women out by saying 'you're getting diabetes, you may have it even after you deliver', then you do say after the fact that you are at a higher risk."*

Attempts to assist women cope emotionally with a difficult pregnancy by shielding them from potential difficulties down the road not only brings up a myriad of ethical issues, it may backfire and further isolate them by contributing to the uncertainty and lack of understanding many of the women in this study expressed when it came to

their health and their baby's health. Aboriginal women, as previously discussed, may disengage from their care providers and become apathetic about education messages and appointment attendance. Many are living in socially isolated environments to begin with. If they sense their health practitioner is not being honest with them, either by withholding information or not believing women's personal experiences, a relationship of reciprocal trust cannot be formed. For women who have already had GDM and delivered a healthy baby, they may not necessarily believe that complications could arise from having it. Stacey, for example, was frustrated with the care she was receiving at the time she was interviewed. She felt her care providers were providing her with conflicting messages that she did not understand and she didn't know what to believe. As she explained, "*they say that [the diabetes] was there before I got pregnant and they say it's going away. Then they say that I have to lose weight. And then, they say that any sore I get won't heal. I don't even want to listen to it anymore.*" Diane was also confused and said, "*gestational diabetes in general: I don't know if it is dangerous 'cause I've never been told if it is or it isn't.*" She was also angry because the dietitian she was seeing did not believe the written food records she was keeping because of her continued weight gain and told her, "*how can I help you if you're not honest with me?*"

Several advisors were also aware of these communication issues. Health care professionals working in a diabetes education centre talked extensively during their focus group about establishing trust with patients through support, mutual respect and reciprocity. As a dietitian, Heather explained, "*they need to talk about things, which gives the level of trust [for them] to be more open and receiving to any recommendations that you might give because you're looking at the whole person in totality and not just the*

disease.” Jane described it this way: *“I think that's important in any therapeutic relationship. You have to understand where the person is coming from, what their perspective is. If you don't take that minute or two to understand that information, then you're just telling someone what they should think and should do. And your chances of success in terms of adherence, is probably lessened.”*

Participants also discussed the importance of taking the time to engage in a reciprocal exchange. Linda said, *“my G.P. is just a fantastic doctor because he sits there and actually listens to his patients. He respects that they know as much about what's going on with their body as he probably does, if not more.”* Over half of the participants, however, had never heard of GDM when they were first diagnosed. Carole explained that she would have appreciated another perspective from someone who had experienced GDM and could *“show you how it is, just to prove that the dietitian isn't just there to tell you what to do.”* Four other women also talked about the idea of a peer or support group for women with GDM to help them better understand its complexities and also to create more awareness in a culturally safe environment. Lori complained that most people in her reserve community *“don't talk about gestational diabetes at all, but I would imagine a lot of people up there probably have it, but where do you go? Where's the support group?”*

Sharon and Faye similarly discussed the possibility of a support group for Aboriginal women with GDM. As Sharon explained, *“because if you don't know anyone else who's had it, you don't know how you're feeling, if how you're feeling is normal. If you're talking to someone who hasn't experienced it, they don't know how you're feeling.”* Faye talked about the idea of being able to identify with an individual who has either gone through a similar experience or is coming from a similar background. On her

own she sought out the support of National Aboriginal Diabetes Association (NADA) located in Winnipeg. At the time, she said: *“when I saw that office, I felt encouraged because I wanted to go there and to be able to feel that, yes, there are some people in the Aboriginal community that are undertaking this responsibility to educate, you know, that community.”* She was disappointed, however, because *“I didn’t see any Aboriginals there.”*

Health care providers, such as Suzanne, a non-Aboriginal prenatal program administrator, sometimes feel uncomfortable interacting with Aboriginal people. She said, *“I don’t have a lot of experiences with sitting around the table with a group of Aboriginal men and maybe women, and I don’t know what they think of me, and I don’t know what to think of them so there’s some uneasiness there.”* Sophia, a community advocate and social worker described similar circumstances based on her work with an inner-city social services agency. She explained that non-Aboriginal health professionals working in the Aboriginal community in Winnipeg do not have the same kind of credibility as another Aboriginal peer to identify with. As she stated, *“you haven’t lived my life.”* Sophia, who is also Métis went on to say, *“I think overall you’re talking about a very disempowered community, so trying to come up with ways to empower them to think that they actually have control in their lives on a variety of factors is pretty challenging.”* Sophia and an Elder, Violet both talked about the importance of trust and changing health professionals’ attitudes towards the strengths of lay teachers from the Aboriginal community to motivate women to move beyond their past and current circumstances. Violet talked about the benefits of healing circles, to speak to women not at a level of education, but instead, *“go to the heart and the spirit of the individual....and perhaps they*

*might develop the courage to speak about what is most pressing and stressful in their lives at the moment.”*

***Leveraging compliance.*** Interactions in a clinical setting with primarily non-Aboriginal health professionals unfortunately do not always provide the opportunity for Aboriginal women to express themselves while coping with GDM. Several practitioners who were interviewed were aware of the potential for miscommunication under these circumstances. A nurse-manager, Allison talked about the delicate balance that needed to be maintained during her interactions with patients at the inner-city clinic where she worked. She commented, *“you have to have a conversation, and it’s a two-way street. You have to feel that there is something being received and given back, and that there’s a transaction happening. It’s more than just you sitting there and loading them with information.”* Other health professionals working in a hospital setting spoke about the concept of *“forced adherence”*, or as Jane explained, *“adherence facilitated through guilt, shame and ridicule.”* In other words the fear or *“scare tactics”* that some health care providers use as leverage to gain compliance and reinforce hierarchy. A colleague of Jane’s, Heather, explained why their health care team doesn’t resort to such tactics: *“they’re not going to come back if you do that. That’s sort of counter-productive.”*

Power struggles between care providers were also described by participants as negatively impacting care and causing distress and confusion. As Stacey said, *“they were too busy trying to scare me to listen to me.”* Several participants discussed their fear and anxiety about GDM that appeared to result from a lack of comprehensive information transferred from care providers. Consequently, some would tend to disengage from the clinical encounter, perhaps to emotionally manage the added stress. Anita already had so

much to deal with in her life having also lost a child to sudden infant death syndrome and raising two grandchildren in addition to her four children. She would often “*forget*” to ask questions when she saw her doctor for GDM and following her son’s birth she said, “*there are still questions that I’d like to ask about it too, like what does it do to your body? I see women with diabetes and they don’t have a leg, you know. Why’s that?*” Lena also found the diabetes education she received complicated. She said, “*I like reading, but I couldn’t get into it. So I can imagine what it’s like for other women that don’t know [how] to read, [are] afraid to ask questions, don’t want to be embarrassed.*”

During their interactions with health professionals, some participants expressed that they felt socially responsible to act more “*outgoing*” during health care encounters in order to feel accepted and respected. Marion talked about this concept of needing to be “*outgoing*” in order to positively adjust to GDM recommendations and feel support and approval from care providers. Marion was not able to achieve this for herself, but recounted the experience of a close friend, “*in her second pregnancy, she listened [to her doctor] and she was more outgoing and that. And she never had gestational diabetes in her second pregnancy although she had it in her first.*” Other participants were more self-assured and assertive, as Lori urged: “*we as patients should be asking, ‘well, why do we need to do that?’ We’ve got to ask questions.*” Linda similarly talked about standing up for herself when confronted by an ultrasound technician about her weight and birthing plan: “*the fetal assessment technician I found her exceedingly rude and obnoxious. She started lecturing me about losing weight. And then, she started talking about how I wasn’t going to be allowed to go to natural childbirth, how I’d be induced, etc. And I looked at her and went, ‘they’re not doing anything I don’t say they have permission to*



*do'.*"

Both Linda and Faye were confident and knowledgeable as they talked about their experiences with GDM, as well as their interactions with health care professionals. Faye had challenged herself to successfully manage her GDM and the type 2 diabetes that developed postpartum. During her interviews she said she felt a need to impart a sense of independence and empowerment in educating other Aboriginal women to confront gestational diabetes in a positive and powerful way. She wanted to know what was happening at every appointment and recommended for other Aboriginal women, "*even if he's in a hurry he can answer a question. If you feel that there is something that's very important for you to learn, you, as a patient, have a right.*" Faye went on to suggest more flexibility when it comes to health promotion and lifestyle intervention:

*I think there should be a promotion of or an awareness made of healthy lifestyle choices that people can make, that can be beneficial for them, because anytime you say 'this has to happen', they're just going to turn a deaf ear because I don't think anyone wants to be told what has to be...and I think that this is very high proportion of people in general. When they're diagnosed with a certain kind of illness, then they just accept that there isn't anything that they can do about it. So I think definitely education, empowering people with knowledge of how they can manage their well-being. I think that's a crucial factor in changing diabetes among not just Aboriginal communities but all communities.*

## **Discussion**

Participants and advisors both described the need for change in the delivery of health services for Aboriginal women with gestational diabetes. Rather than the more commonly cited barriers to care previously reported such as transportation or other socio-economic or logistical problems like long wait times, (Peiris et al., 2008; Wardman et al., 2005) there appear to be other factors at work. According to the group of advisors, divisions in health services as well as the dynamics of patient and caregiver interactions

described by both advisors and participants, may place too great of a burden of responsibility on Aboriginal women to respond to and manage a pregnancy complicated by GDM without the necessary guidance and support from health professionals. Reasons for these circumstances may stem from inconsistent messages in diabetes education resulting from divisions in prenatal health services in Winnipeg. Structural inequalities also appear to exist that present ethical dilemmas and potentially contribute towards the rejection or displacement of care.

Although there has been very little research examining individual barriers to prenatal care for Aboriginal women, Heaman and colleagues have conducted a study also based in Winnipeg. Higher rates of inadequate prenatal care were found in areas with the lowest family income, lowest levels of education achieved, highest percentage of single parent families and the highest percentage of the population reporting Aboriginal background (Heaman et al., 2005 and 2007). A significantly higher proportion of Aboriginal women received inadequate prenatal care (15.7%) compared to only 3.6% of non-Aboriginal women (Heaman et al., 2005). For the group of participants in this study, even though 12 reported having pursued post-secondary education (see Table 6.3), average incomes were below the poverty line, with half of the participants receiving government and/or social assistance.

Like Violet, other authors have suggested that the reasons behind poor health statistics for Aboriginal populations are rooted in a shared history and socio-economic status is not necessarily exclusively to blame (Macaulay, 2009; Peiris et al., 2008; Smith et al., 2005). Mitchell and Maracle (2005) caution against this one-dimensional way of looking at Aboriginal health issues and suggest that health inequalities for Aboriginal

groups cannot be attributed solely or even largely to poverty or individual choices and lifestyles. To take this perspective further stigmatizes Aboriginal people and negatively labels them as unhealthy, poor, uneducated and in compliant when it comes to interactions with non-minority groups such as non-Aboriginal health professionals. As Macaulay writes, “it is important to avoid generalizations” when it comes to Aboriginal peoples and current practices of colonization through negative stereotyping (2009; p.334).

Browne and Varcoe (2006) suggest that a “racialization” of Aboriginal peoples when it comes to health status indicators, or narrow conceptualizations of Aboriginal ‘culture’, as similarly described by Gray and Thomas (2006), make it easy for health care providers to incorporate generalized assumptions into their practice, such as the negative perceptions of poor health and higher risk of diabetes and its visible complications for Aboriginal populations. Risk factors for type 2 and gestational diabetes have the potential to encompass negative stereotypes, as several participants alluded to in this study. Aboriginal women may therefore be viewed as lacking willpower, judgment or moral fortitude (Fiske and Browne, 2006), which severely jeopardizes their self-image and makes them more vulnerable to personal attack and being discredited as “bad” patients or even mothers according to Smith-Morris (2005; p. 152). As a few advisors described as well, Aboriginal women with GDM can be morally judged and condemned for their assumed apathy towards lifestyle changes prescribed. These discriminatory attitudes of implied blame however, in themselves contribute to a lack of compliance and poor attendance patterns reported by Aboriginal women in this study and others. Similar result have also been reported among Aboriginal and non-Aboriginal women with GDM (Evans and O’Brien, 2005; Smith-Morris, 2006). As Evans and O’Brien reported, the negative

stigma associated with GDM was embarrassing for some women and signified that they were unhealthy.

Diabetes education messages were also perceived to be presented by some health care providers in a disrespectful way. According to some participants in this study, several felt they were being blamed for developing GDM and subsequently labeled “at risk.” A qualitative investigation by Lawson and Rajaram (1994) also reported discriminatory practices against non-Aboriginal women with GDM. Another study also based in the U.S. described Aboriginal women as resentful and angry about the way diabetes education messages were delivered. Health care providers were viewed as disrespectful in light of their abruptness and seeming inattentiveness to the concerns and needs of the patient. Many of these participants felt their voices were not heard in the mainstream healthcare system (Dodgson and Struthers, 2005). Similar concerns were reported by Aboriginal women accessing urban health and social services in British Columbia. Women talked about feeling judged and discriminated against solely based upon their Aboriginality. They also described circumstances of racism where negative assumptions were made by health care providers about child neglect and alcohol abuse. Associating gestational diabetes with negative stereotypes may potentially allow health practitioners greater latitude to individualize its management and in doing so may limit their responsibilities for patient attendance and compliance (Kurtz et al., 2008). Bureaucratic divisions within the healthcare system seem to facilitate this with insufficient time or attention spent with women during prenatal care visits according to several participants in this study.

Other studies that have examined health care services for Aboriginal populations

have not discussed divisions of responsibility or their influences on health services. One qualitative study from Australia that looked at patient compliance however recommended that too narrow a focus on cultural differences between Aboriginal and non-Aboriginal populations can easily overlook the impact of institutional arrangements and organizational structures on the nature of provision of service and its uptake. The study found that although the concept of ‘the cultural’ was discussed frequently by the non-Aboriginal participants, there was far less discussion of the ‘institutional’ or the ‘social’ as factors to be addressed in any discussion of Aboriginal health (Humphrey, 2006). The distribution of prenatal care and support services to community agencies described by both advisors and participants accessing the healthcare system in Winnipeg can create organizational structure that is not always accessible to Aboriginal women seeking prenatal care for GDM. In the community, narrow divisions also exist between working towards the empowerment of women through informal teaching, while potentially placing more responsibility on pregnant women. Although community-based programs effectively fill in service gaps and reach women who would not normally seek out formal prenatal care, circumstances can also arise where women are managing their own care with inconsistent and conflicting messages between health care providers in community and clinical settings. Although Faye and Lorna and other studies have described positive instances of self care for women with GDM (Canales, 2004a), administering insulin doses and managing a diabetic pregnancy needs consistent and capable support as one of the advisors, Carolyn, recommended.

Other researchers have reported a lack of trust between Aboriginal patients and their health care providers. Historically Aboriginal peoples have had many reasons not to

trust dominant cultural groups with past discriminatory policies continuing to negatively impact health (Peiris et al., 2008). For women who have also been victims of abuse or had children apprehended, they may be less likely to seek or trust formalized services, especially with the health and care of their families. Aboriginal as well as non-Aboriginal women may not find the model of prenatal care ‘trustworthy’ because of the lack of adequate time to process or communicate their understandings of health messages (Canales, 2004a and 2004b; Dodgson and Struthers, 2005; Long and Curry, 1998). Aboriginal women in British Columbia also complained about “not feeling listened to” by their physicians resulting in a hesitancy to seek out mainstream health services (Kurtz et al., 2008; p.57). For Aboriginal women accessing care for GDM, Smith-Morris (2006) also found that a lack of trust in health professionals may result in patients making diagnostic or medication decisions for themselves, as was described in this study. The anxiety associated with GDM diagnostic uncertainty may also force women to seek out external sources of information for reassurance, according to a non-Aboriginal sample of women (Evans and O’Brien, 2005). Aboriginal women participating in the current study, had similar reactions, however, their motivation was often based on lack of trust often resulting from a negative interaction with the health care system.

Compromised communication patterns that parallel an underlying lack of trust have also been described in the literature. Pima women talked about perceived attitudes of physicians and patients on their reservation. Lack of cultural understanding was blamed for the misinformed perspectives of physicians and withdrawal of women through silence to avoid confrontation with an authority figure. The same study also noted how important a physician’s approach is for women to feel encouragement and

support. Otherwise lower attendance rates may stem from a lack of understanding on the part of Aboriginal women, who may have an altered perception of health risks related to GDM (Smith-Morris, 2006). It takes time and the development of trusting relationships to translate biomedical concepts into personally meaningful messages. Women who are told about their diagnosis with GDM may be offered no other explanation or support (Lawson and Rajaram, 1994). Benoit and colleagues (2003) described the need for a safe, supportive environment for Aboriginal women living in Vancouver. Other authors suggest, as Violet similarly recommended, the need for emotional process, time and understanding through healing circles to draw Aboriginal women out of their isolation (Dodgson and Struthers, 2005; Kurtz et al., 2008; Smith-Morris, 2005).

Imbalances of authority or power were implied or described by participants and advisors that may also negatively impact patient-provider interactions. A nurse Jane referred to the idea of “forced adherence” or scare tactics as a means of coercing compliance. Participants also talked about modifying their personality to find acceptance during health care encounters. Using blame to stigmatize, as described previously, can influence women’s behaviours by wielding power or reinforcing hierarchy. The “scare tactics” referred to by several participants and advisors in this study have also been reported elsewhere as a method of coercing conformity. Participants in Adams’ (2003) qualitative study among Latin American women with type 2 diabetes described similar incidents where scare tactics were used to promote compliance. Patients were scolded and told in graphic detail about the complications of diabetes if they did not maintain appropriate blood glucose levels. Inciting fear in patients such as Stacey and others, however, is often the greatest motivator against accessing health services for Pima

women with diabetic pregnancies (Smith-Morris, 2006). Smith-Morris also warns that visual cues make it too easy for care providers to target and place pregnant Aboriginal women under surveillance (2005). Their position of vulnerability because of the pregnancy itself further isolates and victimizes Aboriginal women as persons “in need” (Fiske and Browne, 2006). This loss of autonomy and decision-making responsibility make Aboriginal women with GDM possible targets of exploitation as well (Browne and Fiske, 2001; Browne and Varcoe, 2006; Oakley, 1980; Sokoloski, 1994).

Under circumstances where the intolerance of unreasonable treatment becomes a negative personality trait (Smith-Morris, 2006), it is easier not to be “outgoing” as Marion described in this study. It requires less interaction when one completely isolates themselves, or lives on the periphery of society, especially for Aboriginal women living in a large urban centre or travelling back and forth from their reserve communities. The ability to exercise self-determination as described by Faye, should not at the same time compromise health, such as self-administering insulin doses. Being able to speak openly and participate in health care decisions through “shared knowledge and power” instead permits reciprocal knowledge exchange and can potentially contribute to personal empowerment (Browne and Fiske, 2001; p.139). Having to gain credibility by transforming one’s behaviour or appearance as described in this study and others is not acceptable (Browne and Fiske, 2001; Fiske and Browne, 2006), and to accept the responsibility for this transformation is to affirm judgements of inadequacy in the eyes of health professionals (Browne and Fiske, 2001). It is a form of biculturalism, which in itself is a source of alienation or marginalization from mainstream culture and society (Dodgson and Struthers, 2005).



## **Recommendations and Conclusions**

The experiences of Aboriginal women with the health care system in Winnipeg points to a need for change in the way prenatal care is delivered for those with GDM. Clinical and community interactions need to be comprehensive, consistent and supportive of Aboriginal women. The shame and stigma associated with the label of GDM must also be dismantled through positive interactions, awareness and education. Practitioners need to present education messages in a positive, non-judgmental way with a focus on the concept of reciprocity, or knowledge exchange. Several participants expressed that they learned the most about GDM from experiencing it themselves. Providers should focus more concentration on this potential in terms of programming and effective self management.

Even though many health professionals follow ethical standards and feel interactions with patients are appropriate, many are unaware of how they may unintentionally demonstrate discriminatory attitudes. As a society, the majority of Canadians have a limited understanding of how historical colonial policies such as residential schools have impacted Aboriginal populations in the way they perceive their own well-being and institutionalized health care (Kurtz et al., 2008; Smith et al., 2005). According to a Society of Obstetricians and Gynecologists of Canada (SOGC) policy statement, barriers facing Aboriginal individuals seeking health care include not only socioeconomic, but attitudinal, structural and communication barriers (Smylie, 2000). As was evident in this study of Aboriginal women seeking care for GDM, attitudinal barriers can include racism and prejudicial assumptions. Prejudice is defined as “incorrect assumptions or stereotypes about an individual based on their racial or ethnic

background”, compared to racism, which can be individual or institutional and includes, “prejudicial behaviour occurring within a context of power inequities” (Smylie, 2000; p.158).

Both the SOGC and the Indigenous Physicians Association of Canada (IPAC) are working toward changing these systemic barriers to care. Several years ago SOGC published a comprehensive “*Guide for Health Professionals Working with Aboriginal Peoples*” (Smylie, 2000). The Canadian Diabetes Association (CDA) “*2008 Clinical Practice Guidelines*” also include a section on “*Type 2 Diabetes in Aboriginal Peoples*” that encourages culturally appropriate care and community partnership (CDA, 2008). IPAC have recently developed a curriculum framework for undergraduate medical students with the aim of requiring that medical educators assist and support emerging physicians in acquiring the skills to engage in health care that is “culturally safe” (IPAC, 2008). The Maori concept of cultural safety is distinct from similar terminology such as cultural awareness, sensitivity or competence, that stress acknowledging or respecting difference (Fiske and Browne, 2006; IPAC, 2008; Kleinman and Benson; 2006; Ramsden, 1990; Smith et al., 2005; Smye and Browne, 2002). Cultural safety includes the practice of self-reflection, or a critical examination of power imbalances which encourages a more patient-centred approach and the establishment of trust, respect as well as open communication (Canales, 2004a and 2004b; IPAC, 2008; Peiris et al., 2008).

Two-way communication, as described by one of the advisors, Allison, could also assist in educating health professionals on Aboriginal women’s personal circumstances. Women’s experiences need to be included in the educational and diagnostic dialogue to introduce personally meaningful concepts and to transition power out of the clinical

setting (Smith-Morris, 2006), which is not always as straightforward as allocating funding into additional resources, education and research. Recommendations such as this will only work towards maintaining the status quo with the power of knowledge continuing to be situated in the organizations, institutions and agencies where it now resides. The participants in this study expressed a need for greater understanding and individual perspective to support themselves and each other, based on their own experiences with GDM. Advocating for more Aboriginal health professionals and community input in health programming would provide women with a more approachable and equitable health care experience.

It should be noted, however, that there are limitations in generalizing the results of this study to other Aboriginal women living in an urban setting or on-reserve. Results may not accurately describe the whole of the population of Aboriginal women living in Winnipeg who symbolize a very diverse sample of cultural groups. The majority of the women recruited for the research were already accessing prenatal or diabetes care independently of this study. Nine women were interested enough in the topic to contact the author on their own. The experiences, therefore, of Aboriginal women with GDM who are either not receiving regular prenatal or endocrine care are not included in these results. Contact was attempted, however, this group of Aboriginal women are an extremely difficult population to reach. In addition, the group of advisors who freely participated in the study, also had an interest in the topic. There were several other health care providers and agencies that were approached, but did not wish to take part formally. Furthermore, given the small sample of advisors, their wide range of opinions are not necessarily representative of the collective group of providers and community advocates

in Winnipeg.

The results of this study, however, do illustrate the divisions of power and attitudinal barriers that exist for Aboriginal women in the city of Winnipeg. Significant numbers of Aboriginal women in Winnipeg are not seeking prenatal care which is a particular concern for those with complicated conditions such as GDM. There is a need for a greater understanding as to why this is occurring (Heaman et al., 2005) because when faced with gestational diabetes, pregnant Aboriginal women living in a large urban centre are vulnerable and in need of trusted assistance and support. They are trusting their health care providers with their life and the long-term health of their families. That trust needs to be respected and reciprocated in the context of cultural safety for mother and child.

Table 6.1. Sample of explanatory model interview questions

<b>Illness Category</b>	<b>Sample Questions</b>
Etiology	Do you think more women are getting gestational diabetes today than in the past? Why or why not?
Pathophysiology	If you had to explain to someone how gestational diabetes works, how would you describe what happens inside your body?
Onset	Can you tell me about how you found out you had gestational diabetes? When did it happen?
Course	Do you ever think that you will have diabetes again?
Treatment	How do you think diabetes during pregnancy should be treated?
Prevention	What do you think a woman can do so she won't get gestational diabetes?

Table 6.2. Description of sample of advisors

<b>Method</b>	<b>Occupation/Background (n)</b>
<b>Focus groups (4)</b>	Hospital diabetes educators (4)
	Hospital diabetes educators (3)
	Inner-city clinic health care practitioners (8)
	Community agency dietitians and outreach staff (4)
<b>Interviews (6)</b>	Nurse/ Inner-city clinic administrator
	Aboriginal outreach worker
	Prenatal program administrator
	Women's health researcher
	Aboriginal community advocate
	Female Elder

Table 6.3. Participant characteristics

<b>Characteristic</b>	<b># of Aboriginal Women (n=29)</b>
<b>Education Level Attained</b>	
Elementary School	2
Some High School	9
Completed High School	6
Some Post-Secondary	12
<b>Reported Annual Income</b>	
\$5,000 – 15,000	9
\$15,000 – 20,000	7
\$20,000 – 30,000	7
\$30,000 – 40,000	3
> \$40,000	3
<b>Marital Status</b>	
Married	5
Common-law	13
Single	11
<b>Occupation</b>	
Homemaker	17
Unemployed	4
Private Sector Employee	5
Government Employee	2
Student	1

Table 6.4: Advisor pseudonyms and profession

<b>Advisor Pseudonyms</b>	<b>Profession</b>
Susan	Dietitian
Cathy	Dietitian
Isobel	Nurse
Anne	Nurse
Heather	Dietitian
Mary	Nurse
Jane	Nurse
Allison	Nurse Manager
Denise	Native Women's Advocate (First Nation)
Brenda	Dietitian
Emily	Dietitian
Karen	Outreach Worker (Métis)
Cheryl	Outreach Worker (First Nation)
Suzanne	Prenatal Program Manager
Caroline	Nurse Researcher
Amanda	Physician
Rebecca	Physician
Megan	Nurse
Barb	Diabetes Educator
Celeste	Midwife
Holly	Midwife
Irma	Nurse
James	Physician
Sophia	Social Worker (Métis)
Violet	Elder (First Nation)

Table 6.5: Participant pseudonyms, diabetes status and residence at the time of interview

Pseudonym Residence	Diabetes Status and Treatment	Prior Pregnancies	
Darlene	GDM with last pregnancy, three years ago; Lifestyle	3	Winnipeg
Tracy*	GDM with previous pregnancy, 7 months ago; Lifestyle	10	Winnipeg
Alice	Currently type 2 after 4 <sup>th</sup> pregnancy with GDM, 4 years ago; Insulin	5	Winnipeg
Marion	Currently type 2 after 4 <sup>th</sup> pregnancy with GDM, 1 year ago; Lifestyle	4	Winnipeg
Sharon	GDM with first pregnancy 1 year ago; Lifestyle	1	Rural MB
Pam	GDM with first pregnancy 4 years ago; Insulin	2	Winnipeg
Dawn*	GDM currently; Insulin	1	Winnipeg
Deb	GDM with previous 2 pregnancies, 1 and 2 years ago; Lifestyle	5	Winnipeg
Carole*	Currently has type 2 after 3 <sup>rd</sup> pregnancy with GDM, 2 years ago; Insulin	3	Reserve
Terri*	GDM with prior pregnancies and currently; Insulin	3	Winnipeg
Eva	GDM with last pregnancy, 2 years ago; Lifestyle	3	Winnipeg
Anita	GDM with last pregnancy, 3 years ago; Insulin	4	Winnipeg
Nancy	GDM with first pregnancy, 3 years ago; Lifestyle	2	Winnipeg
Sandy*	Currently type 2; GDM with last 2 pregnancies, 1 and 2 years ago; Insulin	3	Winnipeg



Tricia	GDM with last pregnancy, 6 months ago; Insulin	2	Winnipeg
Elaine*	GDM with last pregnancy, 3 years ago; Lifestyle	1	Winnipeg
Linda*	GDM currently and with last pregnancy 2 years ago; Insulin	4	Winnipeg
Cindy*	GDM currently; 2 <sup>nd</sup> trimester; Insulin	2	Reserve
Faye	Currently type 2, GDM with last pregnancy, 2 years ago; Insulin	3	Winnipeg
Tina*	GDM currently; Lifestyle	0	Reserve
Lori*	GDM currently and with last pregnancy, 11 years ago; Lifestyle	1	Winnipeg
Amber	GDM with last pregnancy, 3 months ago; Insulin	1	Winnipeg
Lorna*	GDM with current pregnancy; Insulin	2	Winnipeg
Doris*	GDM currently; Insulin	0	Winnipeg
Stacey*	Currently type 2, GDM with last 2 pregnancies, 2 and 4 years ago; Insulin	4	Winnipeg
Veronica*	GDM currently; Insulin	1	Winnipeg
Claire*	Currently type 2; GDM with last 2 pregnancies, 1 and 3 years ago; Insulin	2	Reserve
Lena	GDM with last 2 pregnancies, 3 years and 5 months ago; Lifestyle	7	Winnipeg
Diane*	GDM with current and last pregnancy, 3 years ago; Insulin	4	Winnipeg

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\* Participant pregnant at time of interview

Table 6.6. Summary of main health services themes compared to occupation and family background for advisors and participants

<b>THEMES</b>	<b>Trust</b>	<b>Responsibility</b>	<b>Disengagement</b>	<b>Blame</b>	<b>Apathy</b>	<b>Misinformation</b>
<b>Identity</b>						
Caucasian (n=20)	13	18	16	18	15	15
Saulteaux/ Ojibwe (n=16)	14	13	10	12	12	12
Cree (n=9)	7	8	6	6	4	7
Métis (n=7)	6	7	2	7	5	7
Oji-Cree (N=2)	1	0	0	1	1	2
<b>Occupation</b>						
Health Care Professional (n=19)	11	16	14	16	14	13
Private Sector Employee (n=10)	10	10	10	9	6	8
Public Service Employee (n=3)	3	3	2	3	2	3
Unemployed (n=21)	15	15	11	15	14	17
<b>Participation</b>						
Advisor (n=25)	18	23	19	22	18	19
Participant (n=29)	23	23	15	21	19	24

## Chapter Seven

### Summary

*The women held the power. But I don't mean 'power'. The women were held up by the men. We were held up in reverence because we had this wonderful gift that Creator gave us, and that was the gift of bringing a new child into the world. So that alone was respected by the men. That alone – just having that gift from the Creator was so awesome. If Creator would give us that gift of birthing, then that means that the Creator favoured us, which means who should know better what is good for the people more than the women? So that the gift of creation meant we also had the gift of creation as far as unity in the community was concerned, and what was best for the women, the children and the men. We knew it better than they did. (Violet, Elder)*

The overall purpose of this research project was to describe Aboriginal women's experiences with gestational diabetes mellitus and to what extent cultural understandings are shared among a diverse group of Aboriginal women accessing prenatal care within the city of Winnipeg. Since very little research has been conducted in this area, representative advisors were also consulted to contribute towards a clearer understanding of the context and challenges Aboriginal women with GDM face in an urban Canadian setting. These objectives were accomplished using several qualitative interviews formats. Unstructured interviews or focus groups took place with the advisors and both semi-structured and structured interviews were administered to the Aboriginal women participants. The three papers that make up the central portion of this dissertation comprise the results of the study and collectively emphasize the challenge GDM presents to Aboriginal women, as they attempt to cope and manage the condition in their daily lives. For many of the participants in this study, their already complicated lives were dramatically influenced by the fear, anxiety and frustration that they associated with GDM. In addition, women often felt discrimination in their exchanges with health care professionals, which in several cases further contributed towards an internalization of the shame and stigma associated with GDM. Participants' emotional reactions to GDM also seemed to

negatively influence relationships with food and some women expressed feeling a lack of control in the self-monitoring of BG and other prescribed treatments. These combined circumstances, it was proposed, may have resulted in a social isolation. Women's responses to the EM interview questions and consensus statements were often based on personal experience combined with the more commonly shared integration of biomedical knowledge transferred from health care providers.

This qualitative study, although exploratory in design, provides a starting point to better understand the complex factors that may be associated with rising rates of GDM among Aboriginal women in Manitoba (Aljohani et al., 2008a), and why First Nation and Métis women do not always receive adequate prenatal care in the urban setting of Winnipeg (Heaman et al., 2005). The study also provides insights into Aboriginal women's life circumstances of continual physical transition in an urban setting, the social and perhaps cultural isolation that contribute to the lack of control they feel over so many aspects of their lives, including the concurrent management of diabetes and pregnancy. In the three papers that make up this dissertation, results were presented including the general findings that for this group of Aboriginal women who have experienced GDM:

- a) biomedical understandings are most commonly shared, while personal interpretation of GDM symptoms and outcomes produce a more variable response leading to weak consensus on the topic of GDM among participants;
- b) emotionally mediated eating behaviours may involve inconsistent meals, binging on foods of low nutritional quality, and for some women dangerous practices associated with perhaps pre-existing eating disorders;
- c) communication as well as cultural barriers exist and limit access to and quality of

prenatal care as well as the effective and consistent interpretation of diabetes education messages.

Collectively these results suggest that the experience of living with GDM for most of this group of Aboriginal women was quite overwhelming. There are complex factors at work influencing perceptions and self-reported behaviours that participants generally felt were beyond their control. Divisions in health services, as well as the dynamics of patient and caregiver interactions described, left Aboriginal women feeling like they were managing a pregnancy compromised by GDM completely on their own without educational support. Reasons for these circumstances may partially stem from possible pre-existing perceptions of Aboriginal women by health care providers as well as the divisions or inconsistent messages in diabetes education that were reported.

Even though biomedical explanations for GDM were most commonly shared among the participants, the blame some women associated with a condition that is frequently individualized can also act as a barrier to care. Participants' emotional responses to these circumstances combined with the many other challenges in their lives negatively influence not only health care interactions, but eating behaviours as well as overall motivation to apply therapeutic recommendations. Women's sense of failure or lack of control can therefore result in poor management practices, poor self-image and further isolation or social exclusion. Communication barriers between health care providers, friends and family may also lead to insufficient support in the effective treatment of GDM. As several women expressed, GDM is a lonely experience without the support and understanding of others who have been faced with the same management challenges.

Gestational diabetes, unhealthy eating behaviours and outward appearance were described by participants as being closely tied to self-worth and how women are perceived socially or externally, not only within their families but in the community and among health care providers. It is a negative influence on self-esteem and self-perception as women and mothers and may help to explain why an overall lack of sharing was determined by cultural consensus analysis for this group of participants. There appears to be a lack of sharing stemming from societal, cultural as well as self-perceptions having to do with GDM. Why Aboriginal women do not talk about GDM with each other may reflect the stigma and blame that are so closely connected to diabetes, especially in Aboriginal communities where overall prevalence rates are higher than among the general population. The stigma of having GDM, or the message that ‘being Aboriginal means being diabetic’ can potentially lead to devastating consequences (Ferreira and Lang, 2006). The intent of the statement disempowers individuals and their communities because it blames them for who they are, rendering them inactive. Such a notion can be considered another stereotype and further degrade any sense of pride or positive identity. An embodiment of these constructs also reinforces a vision of Aboriginal women with GDM as “unhealthy”, making it difficult under these circumstances of perceived shame or embarrassment to take on GDM self-management.

Canada’s history of colonization with its resulting racism, discrimination and marginalization continues to affect the health and well-being of many communities (Gracey and King, 2009; IPAC, 2008). To a great extent the medical community encourages a public awareness of family history, obesity, lifestyle and diet as factors that contribute to the onset of gestational diabetes. From a critical perspective, this narrow interpretation could be viewed as an attempt to ignore the macro-social framework of GDM for Aboriginal women. The support they

receive should meet their needs in the larger context of their lives and not be conditional. It should not be tied to pleasing health professionals because if women feel unable to achieve ideal results or blood glucose targets as this study has suggested, they may sense they are hopeless in their efforts or lack control. These circumstances of self-perceived defeat may consequently cause patients to “suppress their true selves” (Hillage et al., 2008: p. 175), or isolate them even further by rejecting or resisting formalized care.

### **Limitations and Implications of the Research**

Based on the results of this study, it is difficult to draw strong conclusions supporting the existence of a shared cultural model for gestational diabetes among the diverse group of Aboriginal women who participated. Although significant differences existed between participants based on attributes such as parity and residence, sub-groups were too small to make valid comparisons. It is also difficult to extend the study’s overall findings and apply them to the larger population of Aboriginal women who have experienced GDM in an urban environment. The wide range of opinions expressed by the voluntary sample of advisors are not necessarily representative of the collective group of providers and community advocates in Winnipeg.

This is the first qualitative study to examine Aboriginal women’s experiences with GDM in an urban context and in doing so identified several perceived barriers to GDM treatment and management, including the potential for miscommunication and misinterpretation between patients and health care providers. Aboriginal women were also often geographically removed from extended families and socially isolated. Personal interpretations of their condition may therefore be limited under these circumstances compared to biomedical explanations. Unlike other qualitative investigations into the experiences of diabetes and pregnancy with Aboriginal women, only a minority of participants in this study considered GDM a “normal” event or a

predictable part of life. Similar coping strategies, however, were described in a study that compared the GDM experiences of Swedish women with those of women born in the Middle-East. Those originating outside of Sweden described more emotion-focused strategies to cope with GDM compared to problem-focused outlook shared by the Swedish women. The coping strategies, such as women's food behaviours in this study, tend to be associated with perceiving a stressor or GDM in this case as uncontrollable. When viewed as controllable, the individual is more likely to adopt coping strategies such as information seeking and use of social support (Hjelm et al., 2007). Differences between groups of women may relate to whether GDM is seen as a disease or a natural part of life (Hjelm et al., 2005).

Instead of focusing on a more generalized message of biomedically-based recommendations in the treatment of GDM, this study suggests that it is important to focus on what Aboriginal women with GDM do or think or feel in approaching their condition. Daniulaityte (2004) similarly found in her study using cultural consensus analysis with diabetic Mexican men and women, a higher level of cultural understanding relates to better control of GDM. It is therefore important to create treatment and prevention approaches that include peer education and informal social gatherings, since a lack of understanding and social support make coping or adaptation strategies difficult. Participants in this study consistently expressed the desire for improved knowledge, increased awareness and the opportunity to share their experiences with GDM. A more reciprocal model of care is therefore proposed to empower Aboriginal women and their extended support system through increased awareness and education, to create a more positive experience for the patient with GDM. Health care providers would similarly benefit from learning more about women's life circumstances and challenges, as noted by several other authors in the context of type 2 diabetes (de Alba Garcia et al., 2007;



Gregory et al., 1999). According to Smith-Morris (2005), elongated conversations between provider and patient allow the provider a voice in the patient's translation of biomedical information into personally meaningful concepts. This may require structural changes in the provision of care and allocation of scarce resources.

The use of cultural consensus theory and analysis in this study was an effective methodology for understanding shared knowledge among this group of Aboriginal women on the topic of GDM, with the results suggesting that increased knowledge and experience are associated with a greater overall understanding and perhaps confidence in women's adaptation response in managing their gestational diabetes. Results from the explanatory model interviews provided personal perspectives supporting the concept that an increased perception of knowledge and control contribute to a decreased sense of frustration, fear or anxiety associated with GDM. The use of Arthur Kleinman's explanatory model framework was effective in this case, to allow a more flexible and culturally situated meanings and interpretations of GDM. These findings are significant for those involved in the treatment of Aboriginal women with GDM. For those with low perceived control, high personal demands and lack of social support, increase levels of stress for patients, with obvious negative influences on health. These findings are supported by the Health Belief Model developed by Rosenstock and colleagues (1988) to explain how health behaviours are influenced by personal perceptions as well as mediating factors. Personal knowledge of GDM, for example, as well as formalized diabetes education in this continuum, affects behaviours indirectly, combined with personal knowledge or experience. An increased perception of self-efficacy contributing to the likelihood of action therefore results in increased control and the likelihood of behavioural change. In other words, individuals who feel they have more control over their health, or GDM in this case, are more likely to follow through with

health related recommendations. Although this model has not yet been used with Aboriginal populations, according to Hjelm and colleagues (2005), growing up in a society with hierarchical relationships resulting in perhaps discriminatory interactions promote less independent behaviour and therefore overall lowered perceptions of self-efficacy.

### **Overall Contributions of Study**

Based on the study's overall results, there is a need for further research to more definitively explain the variation revealed through cultural consensus analysis. Larger numbers of participants would allow for more definitive results and permit further testing of sub-groups, such as First Nation compared to Métis women using the QAP. Less diversity in sample may also establish a greater degree of consensus among participants, although given the relative rarity of GDM and its lack of general discussion, perhaps it was not an appropriate topic for cultural consensus analysis. However, it will continue to be important to involve Aboriginal women living as a minority group within an urban setting in further qualitative research, since the results from this investigation suggest their experiences may be unique compared to Aboriginal women living on reserve. A more in-depth understanding of eating behaviours and barriers to health services for Aboriginal women with gestational diabetes is also urgently required for a more targeted intervention promoting postpartum healthy eating practices to prevent type 2 diabetes.

Increasingly and globally, diabetes appears to be the most prevalent among migrating, socioeconomically disadvantaged and traumatized populations (King et al., 1998). Few studies have addressed relationships between social inequality, poor physical and emotional health, food responses and their combined influence on GDM for Aboriginal women, as attempted by this study. Ferreira and Lang (2006) see this as problem with a restrictive concept of "culture" which tends to focus on behaviours when used in the context of biomedicine. The adoption of a more

expansive concept of culture has been suggested by a number of authors (Browne and Smye, 2002; Gray and Thomas, 2006; O'Neil et al., 1999; Rock, 2003). For instance as Rock (2003) asserts, the concept of "lifestyle" differs dramatically from culture.

This study contributes to a greater understanding of "culture" as it "defines our identity, lends meaning to our lives and offers explanations of actions and events" (Nicolaisen, 2009; p. S9). In the development of culturally safe health policies, programs and future research with Aboriginal women on the topic of GDM, these explanations need to be included. For the Aboriginal women participating in this study, gestational diabetes is intimately linked with lifestyle that includes food behaviours as well as the conflicting perceptions of pregnancy as a gift and an event to be celebrated combined with diabetes as an embarrassment or stigma. Researchers who study health and nutrition behaviour need to be aware that populations do not consistently share the same way of thinking or understanding. Meanings should not be assumed as they not necessarily shared, as knowledge is both distributed and controlled. As Evans and O'Brien (2005) have found for non-Aboriginal women with GDM, success in following a prescribed diabetes regimen arose from self-perceived personal knowledge, personal power and expertise in self-care. Experiential knowledge combined with formalized diabetes education provided women with an inner-strength that also facilitated their success in managing GDM.

Garro has suggested using balance as a basis for explaining how diabetes works and as a means for handling the illness using an approach that is grounded in an understanding of how people interpret and manage their diabetes. She recommends an approach that is positively "geared towards a mutually negotiated understanding of illness process and control" (1987; p. 107). The concept of control perhaps symbolizing in the case of Aboriginal women with GDM, self-efficacy and security in their own interpretation of their condition, knowing there is the

potential for prevention and change. Collectively, Aboriginal women have the power to take control over their lives and gestational diabetes, however these efforts need to be encouraged in a holistic and supportive manner, based on their own experience. There is also the need to advocate for the elimination of blame, guilt and shame that surrounds GDM for many Aboriginal women. As Omura (2006) has noted, there is a stigma associated with diabetes in Aboriginal communities. These negative assumptions need to shift, and create associations that are positively aligned with cultural identity, awareness and understanding. Women play central roles for family and community. There are positive implications for all when women are maintaining their own health (Poudrier and Kennedy, 2008). Aboriginal women want to be accepted and viewed as good mothers, but they do not necessarily receive these messages from those around them especially when they feel they are scrutinized for the way they eat and live their lives. For the Aboriginal women who participated in this study, it is the health of their children they want and need to focus on and be proud of. As women and mothers they have been bestowed with the gift of creation as Violet described, and the power to strive for the unity and health of their families and communities.

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## **Appendices**

### **Appendix A: Introductory Materials**

- **Recruitment Poster**
- **Introductory Letter to Advisors**

### **Appendix B: Interview Guides**

- **Unstructured Guide for Advisors**
- **Semi-Structured Guide for Participants**
- **Structured Interview Statements**

### **Appendix C: Ethical Approvals**

- **The University of Manitoba Health Research Ethics Board**
- **The Health Sciences Centre Research Impact Committee**
- **Winnipeg Regional Health Authority Research Review Committee**
- **Health Canada Research Ethics Board**

### **Appendix D: Consent Forms**

- **Participant Information and Consent Form**
- **Advisor Information and Consent Form**

## **Appendix A**

### **Introductory Materials**

- 1. Recruitment Poster**
- 2. Introductory Letter to Advisors**

## Have you ever been diagnosed with **Gestational Diabetes** (diabetes diagnosed for the first time during pregnancy)?

We are looking for volunteers to take part in a study of **Aboriginal women** who have **currently been diagnosed with gestational diabetes**, or have had diabetes diagnosed for the first time during pregnancy **within the last 5 years**.

We are hoping to learn more about women's experiences with gestational diabetes to help make prevention and treatment programs more effective.

As a participant in this study you would be interviewed in one session, lasting approximately **one hour** and will receive a **gift** for your time. **Transportation will be provided** or the interview can take place in your home.

For more information about this study, or to volunteer for this study, please contact:

Hannah Tait Neufeld

at [REDACTED] or

Email: [umneuf30@cc.umanitoba.ca](mailto:umneuf30@cc.umanitoba.ca)



THANK YOU

This study has been reviewed by, and received ethics approval by the Bannatyne Health Research Ethics Board, University of Manitoba



UNIVERSITY  
OF MANITOBA

Faculty of Medicine

Department of Community Health Sciences

750 Bannatyne Ave.  
Winnipeg, Manitoba  
Canada R3E 0W3

Dear

My name is Hannah Neufeld. I am a doctoral student from the University of Manitoba in the Department of Community Health Sciences. As part of my program I will be doing a research study called "Understanding Aboriginal Women's Experiences with Gestational Diabetes Mellitus." I am interested in learning about Aboriginal mothers' experiences and ideas about support and prenatal care services available in the city. I would like to talk to mothers, health professionals as well as Elders and community leaders here in Winnipeg.

I would like to request the volunteer participation of an interested individual or individuals with your organization and talk to them about this topic. They would also be encouraged to provide feed-back on the interviews topics and study results. By participating in this study, I will arrange to speak with the volunteer(s) for about an hour at their convenience. All of the information I learn from the interview will be kept confidential. I would very much appreciate the chance to speak with members of your organization personally to explain more about the study and to answer any questions.

I may be contacted directly for more information, or to arrange a time to talk. My phone number in Winnipeg is [REDACTED].

I look forward to future discussions.

Sincerely,

Hannah Neufeld,  
Ph.D. Candidate

## **Appendix B**

### **Interview Guides**

- 1. Unstructured Guide for Advisors**
- 2. Semi-Structured Guide for Participants**
- 3. Structured Interview Statements**

## Record of Interview

Code: Advisor: \_\_\_\_\_  
Participant: \_\_\_\_\_

1. Date of Interview: \_\_\_\_\_  
Start: \_\_\_\_\_ End: \_\_\_\_\_ Length \_\_\_\_\_ hours  
\_\_\_\_\_ minutes
2. Physical Setting: \_\_\_\_\_

Interview  Focus Group

### General Directions to Researcher:

\*\*\*Names on Consent Forms only

1. Information and consent forms – **leave copies** with advisors and participants
2. Explanatory model interviews include Parts A, B and C
3. Cultural Consensus Statements



## **Semi-Structured Interview Guide for Advisors**

**(Begin by asking the advisor to state their full name and title of current position)**

1. What would you describe as some of the most significant and challenging issues facing Aboriginal women living in the city (short-term and long-term)? What about pregnant Aboriginal women?
2. What do you think about the health services and prenatal care programs currently offered to Aboriginal women in Winnipeg? What are their strengths?
3. Which health services or programs do you think are well done in the city? Do you think current programming could be improved?
4. What have you heard about gestational diabetes (diabetes that first starts during pregnancy)?
5. Would you consider gestational diabetes to be a significant concern for Aboriginal women in the city? For Aboriginal women living on reserve? Why or why not?
6. How do you think prenatal programming in Winnipeg contributes to an awareness of gestational diabetes?
7. How do you think gestational diabetes affects women? Does it affect their children?
8. How do you think gestational diabetes should be treated?
9. What specific measures would you like to see put in place towards the prevention of gestational diabetes?
10. What do you think about the topics we have discussed today? Is there anything else you would like to add?

## **Focus Group Guide for Advisors**

**(Have advisors individually introduce themselves before beginning questions: ask for full name and title of current position)**

1. What are the barriers, if any, to providing care to pregnant Aboriginal women in Winnipeg?
2. What are some of the strengths of prenatal programs for Aboriginal women as they currently exist?
3. How could current programs be improved? How could they specifically address the growing incidence of gestational diabetes among Aboriginal women?
4. Is there anything further that you would like to add?

## Record of Interview

Code: Advisor: \_\_\_\_\_

Participant: \_\_\_\_\_

1. Date of Interview: \_\_\_\_\_  
Start: \_\_\_\_\_ End: \_\_\_\_\_ Length \_\_\_\_\_ hours  
\_\_\_\_\_ minutes
2. Physical Setting: \_\_\_\_\_

Interview    Focus Group

### General Directions to Researcher:

\*\*\*Names on Consent Forms only

1. Information and consent forms – **leave copies** with advisors and participants
2. Explanatory model interviews include Parts A, B and C
3. Cultural Consensus Statements

## Response Record Sheet

Participant: \_\_\_\_\_

### Part A: Background Questions

1. When and where were you born? (If not from this community when did you move here?)
  - a) Date of Birth: \_\_\_\_\_
  - b) Place of Birth: \_\_\_\_\_
  - c) Time of Arrival in Winnipeg: \_\_\_\_\_
  
2. Have you ever lived away from Winnipeg / this neighbourhood (community)?  
\_\_\_\_\_  
(Where have you lived?)  
\_\_\_\_\_
  
3. Who did you live with when you were growing up?  
\_\_\_\_\_
  
4. Who do you live with now?  
\_\_\_\_\_  
(Who lives in your home?)
  
5. How many children do you have? \_\_\_\_\_  
How many times have you been pregnant? \_\_\_\_\_  
What is the age of each child?  
\_\_\_\_\_
  
6. Did you ever attend prenatal classes or visit someone regularly during your pregnancies?  
\_\_\_\_\_
  
7. Was your first pregnancy different than your last pregnancy?  
\_\_\_\_\_
  
8. Do other people in your family have diabetes?  
\_\_\_\_\_

9. How much formal education do you have? (How long did you go to school or are you still in school?)
1. NO FORMAL EDUCATION
  2. LESS THAN GRADE 7
  3. GRADE 7-9
  4. GRADE 10-12
  5. COMPLETED HIGH SCHOOL
  6. SOME COLLEGE OR UNIVERSITY
  7. COMPLETED COLLEGE OR UNDERGRADUATE DEGREE
  8. SOME GRADUATE WORK
  9. COMPLETED GRADUATE DEGREE
10. How much formal education does your spouse/partner have?  
(Use above codes) \_\_\_\_\_
11. Do you speak any language other than English?  
\_\_\_\_\_
12. Can you tell me about your family's heritage (ancestry)?  
\_\_\_\_\_
13. What religion were you raised in?  
\_\_\_\_\_  
How would you describe your current faith (spirituality)?  
\_\_\_\_\_

## **Part B: Explanatory Model Interview Guide**

I have come today to ask you about your thoughts and ideas about gestational diabetes and talk about the experience of that pregnancy.

1. Thinking back to that time(s) you were pregnant, what do you remember most?

### **ONSET:**

2. Can you tell me about how you found out you had gestational diabetes? When did it happen?
3. How did gestational diabetes affect you once you were diagnosed? (Were you formally diagnosed? By whom?)
4. Do you know of anyone else who has had gestational diabetes?

### **ETIOLOGY:**

5. What do you think caused you to develop gestational diabetes?
6. Do you think more women are getting gestational diabetes today than in the past? Why or why not?
7. What do you hear other people say about gestational diabetes? Do you think anyone knows what causes it?

### **COURSE OF ILLNESS:**

8. How did gestational diabetes affect what you did as part of your daily life (Probe: at different times during your pregnancy? Examples: eating, sleeping, activity, relationships)? What about after you had the baby?
9. Have you experienced any consequences (ie. had to deal with any issues) from having gestational diabetes?
10. Do you ever think that you will have diabetes again?

### **PATHOPHYSIOLOGY:**

11. If you had to explain to someone how gestational diabetes works, how would you describe what happens inside your body?
12. (If participant mentions blood sugar ask:) Can you explain how you felt when your blood sugar levels were too high or too low?

TREATMENT:

13. When you first found out that you had gestational diabetes how was it treated? (Probe: How did the treatments work at different times during your pregnancy and after?)
14. Were there other things that people advised or talked to you about?
15. When you were pregnant were you told how you should eat? What were you told? What did the people you live with think?
16. Did anyone ever talk to you about exercising when you had gestational diabetes? What did they say? Was this advice easy or difficult to follow?
17. What were the most important things you learned about diabetes during your pregnancy? From whom?
18. Are there other things you did to improve your blood sugar levels? (Probe: Were you on insulin?)
19. How do you think diabetes during pregnancy should be treated?

PREVENTION?

20. What do you think a woman can do so she won't get gestational diabetes?
21. Did your experience with gestational diabetes change the way you think about diabetes? Did it change the way you think about your health or your family's health?
22. Do you think there is a role for Elders and (family)/community members in the treatment and prevention of gestational diabetes?
23. What do you think has to happen so more (Aboriginal) women won't get diabetes? (Probe: When should prevention start?)

**Part C: Continuation of Background Questions:**

24. Are you presently: (Circle number)
1. WORKING FULL-TIME
  2. WORKING PART-TIME
  3. UNEMPLOYED
  4. FULL-TIME HOMEMAKER
  5. STUDENT
25. Is your spouse/partner presently: (former partner/spouse)  
(Use above codes) \_\_\_\_\_
26. What is your approximate annual household income?
1. LESS THAN \$5,000
  2. \$5,000 - \$9,999
  3. \$10,000 - \$14,999
  4. \$15,000 - \$19,999
  5. \$20,000 - \$24,999
  6. \$25,000 - \$29,999
  7. \$30,000 - \$34,999
  8. \$35,000 - \$39,999
  9. \$40,000 - \$45,999
  10. \$50,000 OR MORE
27. Do you have any other sources of income other than your salary (s)? 1 YES 2 NO
28. Is there anything else you would like to tell me about yourself, your child(ren) or your family?



## Structured Interview Statements

Please tell me **Yes** or **No** after you have listened to the following questions. They are all based on comments other women have made during their interviews.

### ETIOLOGY:

1. Do you think more Aboriginal women are getting GDM because of poverty (being poor)?
2. Do you think gestational diabetes can be passed down from a mother to her daughter?
3. Do you think women are more likely to get GDM if they are overweight?
4. Do you think women can get GDM from not being active or just sitting around during pregnancy?
5. Do you think GDM can happen to women because of the way they eat?
6. Do you think that if a woman eats too much when they are pregnant they can get GDM?
7. Do you think if women are older when they get pregnant they can get GDM more easily?
8. Do you think that if a woman has GDM there is nothing she can do to stop it, even if she follows a healthy diet?
9. Do you think women who have had GDM will get it with all their other pregnancies?
10. Do you think most Aboriginal people eventually get diabetes because it runs through their families?

### COURSE OF ILLNESS/SYMPTOMS:

11. Do you think that eating foods with a lot of sugar (or starch) in them makes people with diabetes feel tired?
12. Do you think that when people are more active their bodies produce more insulin?
13. Do you think that when women have GDM their blood sugars can cause them to be extra emotional?
14. Do you think that when blood sugars are high, women with GDM may notice their eyes hurting?
15. Do you think that women may react to having GDM by being worried or anxious during their pregnancy?
16. Do you think that GDM can change the colour of a woman's skin when she is pregnant?
17. Do you think that for pregnant women with GDM, stress can make blood sugar levels high?

### TREATMENT:

18. Do you think it is okay for pregnant women with GDM to eat whatever they are craving?
19. Do you think that a woman with GDM should rest when their blood sugars are high?

20. Do you think that it is best for women with GDM to trust their own judgement when making decisions about caring for themselves and their baby?
21. Do you think that going for walks can help women with GDM keep their blood sugars in control?
22. Do you think if a woman with GDM eats mostly meats, she can keep her blood sugars lower?
23. Do you think that if you can't feel that your blood sugar is high you do not need to do anything, like check your blood or take your insulin?
24. Do you think that pregnant women with GDM should just not eat anything as a way to keep their blood sugars from changing?

#### OUTCOMES:

25. Do you think that when a woman is diagnosed with GDM she will have a big baby?
26. Do you think that gestational diabetes is temporary and goes away after the baby is born?
27. Do you think it can hurt the baby if a woman eats too much sugar when pregnant with GDM?
28. Do you think that if a woman does not control her GDM, her baby might be born too early?
29. Do you think a woman's body changes after having GDM and she may have more trouble losing weight?
30. Do you think that if a woman has had GDM, she will be more likely to get type 2 diabetes in a few years time?
31. Do you think that women who have had GDM should worry about their children getting diabetes in the future?

#### PREVENTION:

32. Do you think if women avoid eating certain foods like sugar, white bread and fast foods they won't get GDM?
33. Do you think that being active can prevent GDM?
34. Do you think if pregnant women eat healthy they can prevent GDM?
35. Do you think enough is known about GDM to prevent it?
36. Do you think that there is nothing to be done to prevent diabetes because it comes and goes whenever it wants to?

## **Appendix C**

### **Ethical Approvals**

- 1. The University of Manitoba Health Research Ethics Board**
- 2. The Health Sciences Centre Research Impact Committee**
- 3. Winnipeg Regional Health Authority Research Review Committee**
- 4. Health Canada Research Ethics Board**



UNIVERSITY  
OF MANITOBA

BANNATYNE CAMPUS  
Research Ethics Boards

P126-770 Bannatyne Avenue  
Winnipeg, Manitoba  
Canada R3E 0W3  
Tel: (204) 789-3255  
Fax: (204) 789-3414

APPROVAL FORM

Principal Investigator: Ms. H. Neufeld

Protocol Reference Number: H2006:133  
Date of Approval: October 3, 2006

Protocol Title: "Understanding Aboriginal Women's Experiences with Gestational Diabetes Mellitus"

The following is/are approved for use:

- Protocol dated September 5, 2006

The above was approved by Dr. John Arnett, Ph.D., C. Psych, Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated September 7, 2006. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations*.

A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval should be sought from the relevant institution, if required.

Sincerely yours,

John Arnett, Ph.D. C. Psych.  
Chair, Health Research Ethics Board  
Bannatyne Campus

**Please quote the above protocol reference number on all correspondence.**

Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255 / Fax: (204) 789-3414



Health Sciences Centre  
Winnipeg

Office of the Director of Research

Dial Direct 204-787-2404  
Fax 204-787-4547

November 17, 2006

Ms Hannah Neufeld  
Principal Investigator  
Department of Community Health Sciences  
S113-750 Bannatyne

Dear Ms Neufeld

**RE: UNDERSTANDING ABORIGINAL WOMEN'S EXPERIENCES WITH  
GESTATIONAL DIABETES MELLITUS.**

**ETHICS #: H2006:133 RIC #: RI06:196**

The above-named protocol, has been evaluated and approved by the HSC Research Impact Committee.

The Department of Research wishes you much success with your study.

Sincerely

Karen Shaw-Allan  
Research Protocol Officer  
Health Sciences Centre

cc: Director of Research  
Ancillary Services, Finance Division

MS7 - 820 Sherbrook Street, Winnipeg, Manitoba Canada R3A 1R9

[www.hsc.mb.ca](http://www.hsc.mb.ca)

An operating  
division of the



Winnipeg Regional  
Health Authority  
Office régional de la  
santé de Winnipeg

Affiliated  
with the



UNIVERSITY  
OF MANITOBA



Winnipeg Regional Health Authority  
Office régional de la santé de Winnipeg  
Caring for Health À l'écoute de notre santé

1800 - 155 Carlton St.  
Winnipeg, Manitoba  
R3C 4Y1 CANADA

TEL: 204/926.7000  
FAX: 204/926.7007  
www.wrha.mb.ca

155, rue Carlton, suite 1800  
Winnipeg, Manitoba  
R3C 4Y1 CANADA

TÉL: 204/926.7000  
TÉLÉC: 204/926.7007  
www.wrha.mb.ca

December 7, 2006

Hanna Neufeld  
Doctoral Candidate  
Faculty of Medicine  
Department of Community Health Sciences  
University of Manitoba  
750 Bannatyne Ave  
Winnipeg, MB  
R3E 0W3

Dear Ms. Neufeld,

**Re: Proposal "Aboriginal Women's Experiences with Gestational Diabetes Mellitus"**  
WRHA Reference No: 2006-019

We are pleased to inform you that your research access request for the above-named study has been approved by the Winnipeg Regional Health Authority (WRHA) Research Review Committee pending confirmation that the following conditions are met or agreed to:

- You, your co-investigators, and your research assistants comply with the relevant privacy legislation as indicated below.
  - The Personal Health Information Act*
  - The Freedom of Information and Protection of Privacy Act*
  - The Personal Health Information Act and The Freedom of Information and Protection of Privacy Act*
- ✓ You complete and return the attached Confidentiality Agreement(s) to Cathy Pope, WRHA, 1800 – 155 Carlton Street, Winnipeg, MB R3C 4Y1;
- You submit to our attention any significant changes in your proposal prior to implementation or any significant changes during the course of the study;
- You submit a summary of the final results of the study to the WRHA and provide us with a copy of any publications arising from the study;
- It is an expected courtesy that WRHA will be given a minimum of five working days advance notice of publication or presentation of results with policy implications, in order to be prepared for public response;
- You agree to be accountable for appropriate storage and elimination of material.

Thank you for selecting the Winnipeg Regional Health Authority as the site to conduct your research. Please let us know should you encounter any site-related difficulties during the course of your study.

We extend best wishes for successful completion of your study.

Sincerely, 

Dr. Mike Moffatt  
Executive Director, Division of Research & Applied Learning  
Chair, Research Review Committee  
Winnipeg Regional Health Authority

cc. Dr. B. Postl  
Ms. L. Esposito  
Dr. J. Arnett, HREB

Encl: **PHIA and FIPPA Agreement**



Health  
Canada

Santé  
Canada

Office of the  
Chief Scientist

Bureau de l'Expert scientifique  
en chef

Address Locator #3104A  
Ottawa, Ontario  
K1A 0K9

JAN 18 2007

Ms. Hannah Tait Neufeld  
Doctoral Candidate  
Dept. of Community Health Sciences  
Faculty of Medicine  
University of Manitoba  
750 Bannatyne Avenue  
Winnipeg, Manitoba  
R3E 0W2

Dear Ms. Neufeld:

**Protocol Number:** REB-2006-0044  
**Protocol Title:** Understanding Aboriginal Women's Experiences with  
Gestational Diabetes Mellitus

**Letter of Approval as submitted**

This letter will inform you of the results of Health Canada's Research Ethics Board's ethical review of your application which took place on January 12, 2007.

The Board recommended that the project proceed in accordance with the protocols submitted in the above-referenced application.

Please be informed that, following the receipt of this approval to proceed with the project, Principal Investigators must:

- obtain an annual ethical approval until the research is complete (the approval is given for one year and will expire on January 12, 2008);
- seek re-approval of the Research Ethics Board for any amendment or modification of the approved research protocol or consent form;
- report immediately to the REB Secretariat, any adverse or unexpected events resulting from the research on human subjects; and
- notify the REB Secretariat, upon termination or completion of the project.

.../2

**Canada**

- 2 -

You will find enclosed a copy of the applicable forms for meeting these ongoing obligations and once completed these should be forwarded to the:

Research Ethics Board (REB) Secretariat  
Office of the Chief Scientist  
Health Canada  
Holland Cross, Tower B  
1600 Scott Street, Room 410  
Address Locator 3104A  
Ottawa, Ontario K1A 0K9

Would you kindly confirm that the research will be carried out in accordance with the approved protocol, by signing below and sending a copy of this letter to the REB Secretariat.

If you require further information, you may contact Ms. Yvette Parent, Senior REB Officer at (613) 941-5199. Please cite the file number (REB-2006-0044) on all correspondence pertaining to your application.

Yours sincerely,

Wendy Sexsmith  
A/Chief Scientist

I confirm,

\_\_\_\_\_  
Principal Investigator  
Date:

Attachments:  
Annex 1 - Amendment Request  
Annex 3 - Adverse Event Report  
Annex 3 - Annual Progress Report  
Annex 4 - Completion-Termination



## **Appendix D**

### **Consent Forms**

- 1. Participant Information and Consent Form**
- 2. Advisor Information and Consent Form**



UNIVERSITY  
OF MANITOBA

Faculty of Medicine

Department of Community Health  
Sciences

750 Bannatyne Ave.  
Winnipeg, Manitoba  
Canada R3E 0W3

### Participant Information and Consent Form

**Title of Study:** Understanding Aboriginal Women’s Experiences with Gestational Diabetes Mellitus

**Principal Investigator:** Hannah Neufeld, Department of Community Health Sciences, University of Manitoba, 750 Bannatyne Avenue, Winnipeg, MB, R3E 0W3

**Advisor:** Dr. Gail Marchessault, Division of Research and Applied Learning, Winnipeg Regional Health Authority, 155 Carlton Street, Winnipeg, MB, R3C 4Y1

**Thank you for considering becoming involved in this study.  
The research will help other pregnant women in the future.**

<u>The explanation below may help you understanding the consent better</u>	<u>Consent</u>
<p>I am doing a research study. You can be involved in you agree.</p> <p>The study is about understanding Aboriginal women’s experiences with diabetes during pregnancy or gestational diabetes.</p> <p>I need your “consent” or your “okay” to interview you. Anything you say will be kept private.</p> <p>Please ask any questions you want to.</p>	<p>You are being asked to take part in a research study. Please take the time to review this consent form and discuss any questions you might have with myself, Hannah Neufeld, the Principal Investigator. You may take your time to decide to participate in this study and may discuss it with your friends and family before making your decision. Please ask me to explain if there is anything that you do not understand contained in this consent form.</p>

Participant’s Initials \_\_\_\_\_

<p><b>What is the study about?</b></p> <p><b>The study is about learning more about how Aboriginal women experience diabetes that first starts when they are pregnant.</b></p> <p><b>I will be talking with pregnant women and new mothers who were diagnosed with gestational diabetes in the last 5 years who live in Winnipeg.</b></p> <p><b>I will also talk to people who work with Aboriginal women who are interested in this topic.</b></p>	<p><b>Purpose of Study:</b> The purpose of this study is to better understand how gestational diabetes (diabetes that is first diagnosed during pregnancy) is understood by Aboriginal women who have experienced it. Maternal health care providers and local advisors and activists will also be consulted on this topic. I will be talking to Aboriginal mothers as well as health professionals and community leaders or Elders who work with pregnant Aboriginal women in Winnipeg to get their input on the research process. In total I want to talk with 28 Aboriginal women in the city who are interested in participating in the study, in addition to 6 to 10 key respondents or advisors.</p>
<p><b>What will happen during the study?</b></p> <p><b>If you agree to be part of the study our meeting or interview will last up to 1 hour.</b></p> <p><b>I will need information on you and your family, such as where you were born and how many children you have.</b></p> <p><b>I will also want to talk to you about the pregnancies you have had and your diagnosis with gestational diabetes.</b></p> <p><b>You may also be asked to listen to questions or sentences about gestational diabetes and answer whether you think they are true or false.</b></p> <p><b>All if the interviews will be tape-recorded if you say it is alright. No one outside of the study will ever listen to the tapes.</b></p>	<p><b>Study Procedures:</b> If you take part in the study I will meet with each participant at an agreed upon time and place to ask you questions as part of an interview. One interview lasting approximately one hour will take place with all 28 women. During the interviews, background questions will be asked about you and your family, such as your place of birth and how many children you have. After these questions you will be asked about past pregnancies and your diagnosis with gestational diabetes. During the second part of the interview you may listen to some statements and tell me if you think they are true or false. With your permission I will tape record the interviews. Although I will try and write down responses as well, the results from the interviews will more accurately represent your words if they are tape-recorded. All of the tapes will be erased at the end of the study.</p>
<p><b>Safety Issues</b></p> <p><b>Even if you are pregnant it is safe to participate in this study.</b></p> <p><b>You only need to give a bit of time.</b></p> <p><b>If you do not want to talk about some things brought up in the interviews, you do not have to.</b></p>	<p><b>Risks and Discomforts:</b> All research carried out by the University must describe any risks or discomfort associated with participating in a study. The only potential problems this study may cause are taking up your time to answer questions as well as bringing up topics that you may not wish to talk about. You do not have to answer any question you do not want to. If you would like to stop the interview or skip a question at any time just ask me.</p>

<p><b>How will the study help?</b></p> <p><b>It might be helpful for you to talk about your experiences with gestational diabetes or it may not.</b></p> <p><b>You will receive a small gift for your time.</b></p> <p><b>You will help researchers and other people who work with Aboriginal women to learn more about gestational diabetes so they can work at better ways of preventing or treating it.</b></p>	<p><b>Benefits:</b> There may or may not be any direct benefit to you from participating in this study. You will not receive any payment for your participation, only a small gift. I hope, however, that the information learned from the interviews will help health professionals working in Winnipeg and reserve communities to better understand Aboriginal women's concerns about gestational diabetes and work towards better ways of treating and preventing it. A summary of the study results will also be prepared and shared with all participants.</p>
<p><b>All of your personal information will be private.</b></p> <p><b>Your name will never be used in the study report. No one outside of the study will know who you are.</b></p> <p><b>All of the tapes and typed-out versions of what you said during the interview will only be available to me or my advisor.</b></p> <p><b>Tapes will be destroyed and thrown away once the study is over.</b></p>	<p><b>Confidentiality:</b> Information gathered in this research study may be published or presented in public forums, however, your name and other identifying information will not be used or revealed. Records of the interviews will be coded only with a number in order that none of the records could be identified with a name. None of the cassettes, nor the final transcripts made of the interviews will be shared with anyone other than myself, the primary investigator or my advisor. The consent form will be the only record with your name on it and will be stored, along with the tapes and transcripts, in a secure and locked location. Upon completion of the study all of the interview recordings will be destroyed. A report of the findings and any subsequent publications will not mention your name or provide any description that might identify you. Despite efforts to keep your personal information confidential, absolute confidentiality cannot, however, be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.</p>

Participant's Initials \_\_\_\_\_

<p><b>You would be volunteering to be a part of this study.</b></p> <p><b>If you decide to drop out of the study at any time that is your right.</b></p> <p><b>Anything you say or do will not affect your health care now or in the future.</b></p>	<p><b>Voluntary Participation / Withdrawal from the Study:</b> Your decision to take part in this study is completely voluntary. You may refuse to participate or you may withdraw from the study at any time. If you decide not to participate or drop out of the study, this will not affect your health care now or in the future. Any health centre or clinic you attend will only receive a summary report about the whole project and will not know any specific information about your interview.</p>
<p><b>Please feel free to ask questions at any time.</b></p> <p><b>Sign the next page of the form only when you are sure you understand everything.</b></p>	<p><b>Questions:</b> You are free to ask to ask any questions that you may have about your rights as a research participant. If questions come up either during or after the study please feel free to contact Hannah Neufeld at [REDACTED] or my advisor Gail Marchessault at [REDACTED]. For further questions about your rights as a research participant you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204)789-3389. Do not sign this consent form until you have had a chance to ask questions and have received satisfactory answers to all of your questions.</p>

Do not sign this consent form unless you have a chance to ask questions and have received satisfactory answers to all of your questions or concerns. Please read the form carefully before you sign it. I would be happy to answer any questions for you or explain anything in more detail.

Participant's Initials \_\_\_\_\_

**Statement of Consent:**

I have read this consent form. I have had the opportunity to discuss this study with Hannah Neufeld and have had my questions answered in language I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this study. I understand that information regarding my personal identity will be kept confidential. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Participant's Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

\_\_\_\_\_  
Investigator's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Investigator's Printed Name

**Participant's Initials** \_\_\_\_\_



UNIVERSITY  
OF MANITOBA

Faculty of Medicine

Department of Community Health  
Sciences

750 Bannatyne Ave.  
Winnipeg, Manitoba  
Canada R3E 0W3

**Title of Study:** Understanding Aboriginal Women's Experiences with Gestational Diabetes Mellitus

**Principal Investigator:** Hannah Neufeld, Department of Community Health Sciences, University of Manitoba, 750 Bannatyne Avenue, Winnipeg, MB, R3E 0W3 [Tel: ██████████]

**Advisor:** Dr. Gail Marchessault, Division of Research and Applied Learning, Winnipeg Regional Health Authority, 155 Carlton Street, Winnipeg, MB, R3C 4Y1 [Tel: ██████████]

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You are being asked to take part in a research study. Please take the time to review this consent form and discuss any questions you might have with myself, Hannah Neufeld, the Principal Investigator. You may take your time to decide to participate in this study and may discuss it with your friends and family before making your decision. Please ask me to explain if there is anything that you do not understand contained in this consent form.

**Purpose of Study:** The purpose of this study is to better understand how gestational diabetes, which is defined as diabetes that is first diagnosed during pregnancy, is understood by Aboriginal women who have experienced it. Maternal health care providers and local advisors and activists will also be consulted on this topic. I will be talking to Aboriginal mothers as well as health professionals and community leaders or Elders who work with pregnant Aboriginal women in Winnipeg to get their input on the research process. In total I want to talk with 28 Aboriginal women in the city who are interested in participating in the study, in addition to 6 to 10 key respondents or advisors.

**Study Procedures:** If you take part in the study I will meet with each advisor at an agreed upon time and place to ask you questions as part of an interview or informal focus group. These meetings should last approximately one hour, will be conducted with each advisor or group of advisors. During the interviews, the advisors will be asked to reflect on issues and impacts of maternal health care services and supports for pregnant Aboriginal women with gestational diabetes in the city of Winnipeg. With your permission I will tape record the interviews. Although I will try and write down responses as well, the results from the interviews or focus groups will more accurately represent your words if they are tape-recorded. All of the tapes will be erased at the end of the study.

**Risks and Discomforts:** All research carried out by the University must describe any risks or discomfort associated with participating in a study. The only potential problems this study may cause are taking up your time to answer questions as well as bringing up topics that you may not wish to talk about. You do not have to answer any question you do not want to. If you would like to stop the interview or skip a question at any time just ask me.

**Benefits:** There may or may not be any direct benefit to you from participating in this study. You will not receive any payment for your participation. I hope, however, that the information learned from the interviews will help health professionals working in Winnipeg and reserve communities to better understand Aboriginal women's concerns about gestational diabetes and work towards ways of treating and preventing it. A executive summary of the study results will also be prepared and shared with all participants.

**Confidentiality:** Information gathered in this research study may be published or presented in public forums, however, your name and other identifying information will not be used or revealed. Records of the interviews will be coded only with a number in order that none of the records could be identified with a name. None of the cassettes, nor the final transcripts made of the interviews will be shared with anyone other than myself, the primary investigator or my advisor. The consent form will be the only record with your name on it and will be stored, along with the tapes and transcripts, in a secure and locked location. Upon completion of the study all of the interview recordings will be destroyed. A report of the findings and any subsequent publications will not mention your name or provide any description that might identify you. Despite efforts to keep your personal information confidential, absolute confidentiality cannot, however, be guaranteed. Most specifically for those participating in focus groups, absolute confidentiality cannot be guaranteed. Under these circumstances it is important to respect the privacy of the other individuals sharing information with the group. In addition, your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

**Voluntary Participation / Withdrawal from the Study:** Your decision to take part in this study is completely voluntary. You may refuse to participate or you may withdraw from the study at any time. If you decide not to participate or drop out of the study, this will not affect your position or employment. Your workplace or organization will only receive a report about the whole project and will not know any specific information about your interview.

**Questions:** You are free to ask to ask any questions that you may have about your rights as a research participant. If questions come up either during or after the study please feel free to contact Hannah Neufeld at [REDACTED] or my advisor Gail Marchessault at [REDACTED]. For further questions about your rights as a research participant you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204)789-3389. Do not sign this consent form until you have had a chance to ask questions and have received satisfactory answers to all of your questions.



**Statement of Consent:** I have read this consent form. I have had the opportunity to discuss this study with Hannah Neufeld and have had my questions answered in language I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this study. I understand that information regarding my personal identity will be kept confidential. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

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Participant's Signature

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Date

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Participant's Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

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Investigator's Signature

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Date

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Investigator's Printed Name