## University of Alberta

Surveillance Stories: Gestational Diabetes and the Intersection of the Clinic, Traditional Chinese Medicine, & Asian Women in Edmonton

by

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A thesis submitted to the faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of *Master of Arts* 

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## List of Abbreviations

ADA American Diabetes Association

BM Biomedicine

CDA Canadian Diabetes Association

DAEAG Department of Anthropology Ethics Advisory Group

EM(s) Explanatory Model(s)

HREB Health Research Ethics Board

GD Gestational Diabetes

TCM Traditional Chinese Medicine

This thesis examines the conceptualizations of gestational diabetes (GD) from the perspectives of three key stakeholder groups in Edmonton: biomedical professionals, a doctor of Traditional Chinese Medicine (TCM), and Asian immigrant women who have lived with GD. The goal is to highlight the differences and similarities between the explanatory models (EMs) of these expert groups and explore the implications for providing culturally appropriate treatment and prevention programs to a diverse population<sup>1</sup>. The focus of this research was stimulated by concerns voiced by the staff of the Diabetes Outpatient Clinic at the Prairie Hospital, whose role includes assisting culturally diverse women in the management of GD<sup>2</sup>. They reported a disproportionate number of women they identified as 'Asian' employing their services and expressed uncertainty in assisting this population with appropriate treatment and prevention programs. Clinical staff requested help in providing culturally appropriate care. While in some sense, the ethnographic setting is the city of Edmonton, Alberta, Canada, the main facet of this ethnographic space was the zone of contact for the gestationally diabetic woman and the health professionals who assist her: the Clinic at the Prairie Hospital.

To varying degrees, the stakeholders and their ideas about GD are connected via the 'contact zone' of the Clinic (Pratt 1993). In her work on imperial travel writing, Pratt defines contact zones as "...social spaces where disparate cultures meet, clash, and grapple with each other, often in highly asymmetrical relations of domination and subordination..." (1993: 4). This definition can be applied to the Clinic as it represents the dominant institution of Biomedicine and constitutes an environment in which diverse groups of people come together, interact, and have the potential to affect one and other. The Clinic represents the phenomenological and

<sup>&</sup>lt;sup>1</sup> Here, the term 'stakeholder' refers to an individual who has a vested interest in GD research due to their occupation or experience with the condition. The term 'expert' refers to an individual who has special knowledge or skills related to GD, such as health care professionals, or a woman who has lived experience with the condition. The three groups who participated in this research can be considered both stakeholders and experts.

<sup>&</sup>lt;sup>2</sup> The name of the hospital where I conducted this research has been changed to protect the anonymity of participants. The Diabetes Outpatient Clinic will be referred to as the Clinic for simplicity.

physical space, or contact zone, between the interactions of women with GD and the biomedical system that is supposed to help them and their infants

## The Diabetes Outpatient Clinic

In this chapter, I describe the key elements of the ethnographic setting of the Clinic: its history, mandate, as well as physical and personnel attributes, as experienced by a gestationally diabetic woman. The Capital Health Region of Edmonton designated the Prairie Hospital as a 'Centre of Excellence' in women's health. The Clinic is located in the Women's Health Centre, whose health care professionals specialize in gynaecology and obstetrics, reproductive health and infertility, as well as prenatal care (Capital Health Authority 2004). The Clinic had been started based on the need for diabetes education and management and had officially opened its doors in May 1987 (LAW Interview 04/08/03).

The primary objective of the Clinic is to provide patient education based on the principle that individuals with diabetes require information, resources, and the necessary self-care skills to successfully manage their condition. Based on this model, the assumption is that the optimal means for GD management is through education and access to a multidisciplinary team of experts, including physicians, nurses, dieticians, pharmacists, and social workers. This team provides up-to-date, accurate diabetes information in the hope that it will be internalized and utilized by patients to effectively cope with their condition. The Clinic specializes in all forms of diabetes education, including Type I and Type II diabetes, and offers a gestational diabetes class for newly diagnosed women and follow-up care until delivery (Diabetes Outpatient Clinic Final Proposal 1986). The Clinic operates Monday through Friday, from 7:30 a.m. to 3:30 p.m. and has three gestational diabetes classes a week on Mondays, Thursdays, and Fridays. A woman is referred to the Clinic by her family physician or obstetrician when diagnosed with GD, which marks her entry into the contact zone and ethnographic setting of this research.

The key points of contact in this ethnographic setting are the physical space of the Clinic, the gestational diabetes class, and follow-up appointments with clinical

staff<sup>3</sup>. I make this set of events and zones of contact understandable by offering a 'day in the life' description based on three composite characters I call June, Barb, and Lydia. This narrative description is based on a compilation of two sources: the interviews I conducted with research participants and my own observations at the Clinic, which I documented in my field notes, including my participation in a gestational diabetes educational class and one particular woman's follow-up appointment with clinical staff. Even though June, Barb, and Lydia are composite characters, this narrativisation of several real women allows me to accurately represent the ethnographic setting of this research as well as the real experiences of women living with GD while ensuring that no particular woman can be identified.

This narrativisation is told from the point of view of June who encounters Barb and Lydia during the gestational diabetes class. June is represented as a Canadian born woman of Asian descent. This is because I was unable to speak with any immigrant women while I visited the Clinic or participate in direct observation due to ethics approval restrictions, which will be discussed in Chapter 2.

## June Visits the Clinic

June is a young and healthy woman who was anxiously awaiting the birth of her first child, due in three months. June and her husband were concerned when her obstetrician diagnosed her with GD. Her doctor referred her to the Clinic at the Prairie Hospital to take a class on GD and to continue follow-up care until delivery. The doctor set up the appointment and instructed June to go to the Clinic the next day by 7:45 a.m.

June followed her doctor's orders and her sister drove her to the Women's Health Centre, arriving there by 7:30 a.m. June took the elevator to the second floor and followed the signs down the hallway to the Clinic. At the end of the hall, she entered a space that was brightly lit, with walls painted pink. June was surprised by how quiet the Clinic was, which contrasted her expectations of a busy hospital ward and crowded waiting room. To her left, June noticed three offices, two for the

<sup>&</sup>lt;sup>3</sup> I did not sit in during or observe any woman's initial appointment at the Clinic with the dietician, nurse, and doctor, due to my own shyness as a novice researcher and because clinical staff did not offer me the opportunity. Here, I present observations I made while visiting the Clinic, participating in the gestational diabetes class, and sitting in on follow-up appointments.

nurses and one for a dietician, and an additional room with a sign above it reading, 'Coffee Room'. She could smell coffee brewing. The receptionist's desk was located to her right and the patient waiting room was positioned directly opposite the desk, with a secondary hallway extending east and separating the two areas. She walked over to the desk and a friendly woman behind the counter asked for her contact information and created her medical chart on a computer. June provided information including her address, Alberta Health Care number, obstetrician's name, and allergies. The receptionist told her to help herself to a coffee or glass of water from the Coffee Room and to have a seat in the waiting room. Later, during the GD class, June learned that the Coffee Room was open to staff, patients, and visitors.

The Coffee Room was spacious, L-shaped, with large windows along the west wall, providing ample light. As June entered the room, she noticed a shelf to the right with a display of several empty cartons and cans of food. Each drink box, can, and carton had its nutritional information label highlighted. In addition, there were several examples of foodstuffs endorsed and labelled by the Canadian Diabetes Association. Along the walls were posters about diabetes management, each depicting smiling people eating a variety of foods. In the middle of the room were several large tables and chairs and to the side was a small kitchen with a microwave, two sinks, disposable cups, as well as some muffins and digestive cookies. June helped herself to a coffee and a cookie and then walked to the waiting room.

Similar in design to the Coffee Room, the waiting room was also L-shaped, but much darker as it had no windows to offer natural sunlight. Classic 'waiting room styled' chairs lined the side and back walls of the room and located in the corners were end tables. There were two big, comfortable reclining chairs, like the kind you would find in a living room, placed in the right corner of the room. Beside these chairs were a low table, two small chairs, and a milk crate full of toys and building blocks for children. Instead of taking a seat, June walked around the waiting room and noticed on the back wall a picture of clinical staff with a certificate beside it reading, "Patient Support Services: The 2002 Reach Award for Teamwork". Along the right wall was a bookshelf full of informational pamphlets, posters, and magazines. June leafed through these and found information on diabetes and heart disease, take-charge management, diabetes support groups, fund-raising events, and

membership application forms for the Alberta Foundation for Diabetes Research. All the information was written in English. June selected a couple of pamphlets and took a seat. She noticed two other pregnant women signing in at the receptionist's desk. Shortly after, a nurse called June's name and escorted her into an office.

The nurse began the appointment by reading aloud June's glucose values from the lab test sent over by her obstetrician, but June did not know what the numbers meant. The nurse asked June, "How many weeks pregnant are you? How many pregnancies have you had? Is there a history of diabetes in your family"? June answered that she was 28 weeks pregnant with her first child and that she had never known anyone with diabetes before. The nurse took notes on a piece a paper in a file folder. Next, the nurse explained to June that they are, "...risk factors associated with the increased probability of developing GD, including family history of diabetes, lack of exercise, and unhealthy diet". The nurse had directed the conversation to this point but then asked June if she had any questions, to which she replied, "No". Their meeting lasted approximately six minutes and then the nurse escorted June back to the waiting room.

June sat in the waiting room not knowing what to do next. After approximately ten minutes, the dietician, who appeared more serious than the nurse, called June into her office. She asked June to stand on a scale and she recorded her weight and height. After, she took a seat across from the dietician who said to her, "Describe your eating habits for me". This led June to confess, guiltily, that she often missed meals due to lack of appetite and time, enjoyed foods high in sugar, and ate an insufficient amount of fruits and vegetables. The dietician disapprovingly acknowledged this eating pattern as common and explained the importance of eating "...smaller, more frequent meals, in order to maintain normal blood glucose values". Their meeting lasted eight minutes and the dietician asked June to go back to the waiting room.

It was 8:30 a.m. when June returned to the waiting room and she saw two other pregnant women. One of them immediately introduced herself as Barb and complained about the ridiculously early time of her appointment at the Clinic. June laughed in agreement and then asked Barb if she had GD too. Barb replied that her obstetrician had called her yesterday morning with the news about her diagnosis and

end when the nurse walked in. She gave each woman a One Touch Ultra glucose meter, courtesy of the Clinic, but asked that they return their meters as soon as possible after delivery so that new patients could use them. The nurse handed each of them an informational pamphlet and asked if they required it in a language other than English. The third woman, whose name was Lydia, said, "Vietnamese", but the nurse said they only had translations in Cantonese or Mandarin. Then the nurse asked the women to follow her without giving them a chance to look at their meters and pamphlets or to ask any questions.

June and the other two women followed the nurse down the second hallway extending east between the receptionist's desk and waiting room. June noticed three examination rooms to the right and three doctor's offices just beyond. To the left were two spacious classrooms and the nurse led the women into the second of the classrooms. In the centre of the room, small tables were arranged to form a large square with a space in the middle. Large windows lined the north wall and June noticed the other walls were lined with teaching materials and equipment, including blackboards, conference writing flip charts, and audio-visual equipment, including a TV and VCR. The nurse asked the women to have a seat and explained that they would be taught about GD as a group.4 Next, she asked Lydia if she was comfortable taking the class in English and explained that an interpreter, provided by the hospital free of charge, could be paged. Lydia nodded and the nurse took this to mean that she did not need a translator. The nurse told her that she could bring a family member or friend to her follow-up appointments or an interpreter could be set up ahead of time if that would make her more comfortable. Lydia continued to nod, saying nothing.

The nurse began the class by acknowledging the fear most women felt about GD and the possibility of injecting insulin. She assured them that small changes to lifestyle were often enough to manage the condition without insulin. June listened intently but noticed that Lydia was staring down at the desk. The nurse provided them with and reviewed another pamphlet developed by the Medical Director of the Clinic. It covered topics such as what is GD, why it happens, the risk factors for its

<sup>&</sup>lt;sup>4</sup> Typically, participation in the gestational diabetes class is limited to three women whenever possible.

onset, treatment options including insulin, breastfeeding, and future health advice.<sup>5</sup> June decided not to ask any questions because she could review the information at home.

The nurse explained how to use the blood glucose meter to test blood sugar levels and June felt her anxiety, in fact the level of anxiety in the room, increase. The nurse demonstrated by taking a pen-like needle, pressing it against her finger, and pushing down to puncture the skin. She pinched her finger in order to pool a small drop of blood, smeared the blood onto a 'strip', which she had taken from a box before poking her finger and which resembled a thin stick of gum, and inserted it into the meter. She showed the women the numerical value displayed on the screen and explained that they had to write down this value in a logbook every time they tested their blood. She told them that they were to test their blood at specific intervals: once before breakfast and two hours after breakfast, lunch, and dinner for a total of four times a day.

Next, the nurse asked each woman to test her blood glucose levels with her meter. June was nervous but was able to do the procedure with hardly any prompting from the nurse. She was surprised that the prick on her finger did not hurt as much as she had thought it would. In contrast, when Lydia attempted to test her blood, the nurse had to review every step with her. It seemed obvious to June that Lydia had not understood the instructions the nurse provided. June felt more comfortable testing her blood sugar because of the demonstration and practice trial but she wished she had brought some paper to take notes in case she forgot any steps later on when she was at home.

Indeed, a notebook would have come in handy when the nurse began explaining the fine details of testing blood glucose levels accurately. She explained that the boxes of strips used to smear the blood onto and insert into the meter were labelled with a batch number and that this number had to match the one on the meter. Otherwise, the value displayed on the screen of the meter would be invalid. Also, a test solution was to be used initially in place of blood, to ensure that the meter was working properly. The nurse did not mention how often this had to be done and June did not think to ask. Lastly, the needles had to be disposed of safely,

<sup>&</sup>lt;sup>5</sup> The pamphlet was available in English only.

preferably in a glass jar with a secure lid. June wondered what to do with the jar once it was full.

The nurse gave each woman a logbook to record her blood glucose values each time she tested. She had written on the back of the logbooks the numerical values indicating the normal range for blood sugar, which is four to seven. She explained that the logbook and meter had to be brought to each follow-up appointment for the clinical staff to review. June decided that this would be easy enough to do since the meter and logbook were fairly small and could fit easily into her purse. Next, the nurse gave the women a list of supplies they needed to test their blood glucose and instructed them to take the list to a pharmacy immediately after class so they could begin testing the next day. June was worried that she would not have time to go to the pharmacy that day because she was scheduled for an eighthour shift at work, directly after the course. The nurse noted that the strips needed to test their blood glucose levels were expensive and not covered by Alberta Health and Wellness or by Blue Cross. Also, a prescription from their family physicians might be required for private insurance companies to cover the cost.

After demonstrating how to test blood glucose levels using the meter, the nurse told the women that they must also test their urine for ketones every morning before breakfast. June had never heard of ketones before and she glanced over to Barb and Lydia, only to see that they looked just as bewildered. The nurse explained that, "...testing ketones was necessary to ensure that the foetus was receiving enough nutrition". Testing required the use of strips different from those used with the blood glucose meter. The nurse showed the women a box of ketone strips, which had a colour chart on one side. The women were instructed to place a ketone strip into the flow of urine at the start of the stream and then compare the colour displayed on the strip to the colour chart provided on the box. Ketones should be negative, which meant that the strip displayed no change of colour. The nurse told the women that if their strip showed a change of colour two days in a row, they were to contact the dietician immediately for consultation. However, she did not explain what the change of colour two days in a row meant for the health of the foetus. June was surprised how quickly the nurse stood up and told them their session was over.

She left immediately, without asking if the women had any questions, and the dietician entered the classroom shortly afterwards.

The objective of the dietician's session was to teach the women proper nutrition skills and appropriate meal planning. She instructed the women to adopt a 'grazing pattern' of eating, going no longer than two to three hours between meals or snacks. They were advised to make lower fat choices and avoid cold cereals during pregnancy as these could dramatically elevate blood sugar levels. Based on their individual meetings earlier that morning, the dietician had developed meal plans for each woman. June was interested to see her plan but then Barb stated that she hated diets. The dietician responded flatly that this was "...not a diet but rather the proper way of eating". For their meals and snacks, the women could select foods from three groups: Carbohydrates, Proteins, and Fats. June wondered what had happened to the four food groups of Fruits and Vegetables, Milk and Diary Products, Meats and Meat Products, and Grains and Cereals. June's meal plan consisted of three meals and two to three snacks throughout the day. For example, at breakfast, June should eat two carbohydrates, one protein, and one fat.

The dietician visually demonstrated appropriate serving sizes for the three food groups by using plastic models of food stuffs, including a quarter of a bagel, an apple, and a piece of meat the size of a deck of cards. June and Barb looked at each other in dismay when they learned that a sliced bagel cut in half was one serving of carbohydrates. The dietician showed the women how to read the nutritional information by using empty cans and cartons of food as examples. She handed June a container of Crystal Light and asked her to read how many calories, carbohydrates, proteins, and fats were in one serving. June completed the task successfully and was happy that Lydia got her can of tuna correct. Suddenly, the door to the classroom opened and a physician appeared. The dietician did not flinch or even skip a word when the doctor asked Barb to come with him.

The dietician continued without Barb and gave June and Lydia several other handouts regarding proper nutrition during pregnancy. The first handout outlined food safety and discussed the potentially harmful affects of consuming too much fish. The instructions directed women to limit their consumption of shark, swordfish, and fresh or frozen tuna (excluding canned tuna) to one meal per month.

The second handout focused on discomfort during pregnancy and suggested ways to relieve nausea, vomiting, and heartburn. The third handout was a list of 'Free Extras'. These were foods that did not drastically affect blood sugar so the women could have as much of them as they wanted. Examples of 'Free Extras' included water, garlic, horseradish, mustard, consommé, Soya sauce, and ginger root. The dietician instructed the women to keep a food diary in accordance with their individualized meal plans and to bring it to their follow-up appointments for her to review. Barb returned to the classroom and the dietician gave her the handouts but did not discuss them with her. Next, the dietician put on a video entitled, "Gestational Diabetes: You're in Control" (1994), turned off the lights, and left the room.

June watched as the video depicted the experiences of five women newly diagnosed with GD. During a mock doctor's appointment, a Caucasian woman expressed concern that her baby would be deformed and that her husband would catch GD. The physician assured her that neither would happen. Another reenactment showed an Eastern European woman who was relieved when the doctor explained that, "...a bad scare or the evil eye could not cause GD". During another appointment, he stated that, "...insulin was not addictive and did not cause blindness" or complications while breastfeeding. Next, the physician explained the pathophysiology of GD from a biomedical perspective. The explanation was accompanied by a visual 'enactment' of the processes in the body. The placenta's hormones inhibited the effectiveness of insulin in moving glucose from the blood stream into cells, resulting in high blood sugar in the mother. The foetus began producing insulin at twelve weeks gestation and attempted to use the extra glucose in the mother's blood stream, "...resulting in an overweight baby".

One woman told the doctor she wanted her baby to be big and healthy. The doctor responded that having an overweight baby could lead to complications, like Caesarean section, premature birth, respiratory problems, still birth, and low blood sugar. Another woman asked, "What can the doctors do for me and my gestational diabetes"? The physician responded, "Nothing. It is up to you to listen and learn what you need to do". The woman is told that she can control her GD by closely following the recommended treatment: maintain her individualized meal plan,

monitor blood sugar, exercise, manage stress, and keep a detailed log of daily food intake, exercise levels, and blood sugar values for her doctor to review. The video ended and the doctor called June into one of the examining rooms.

The doctor introduced himself, shook June's hand, and asked her to have a seat on the examining table. He took her blood pressure and pulse rate and measured her belly from pelvis to sternum with a tape measure to determine if the foetus was within a normal size range. After the physical examination, June sat up and the doctor reviewed her blood glucose and plasma levels from her lab test sent over by her gynaecologist. Next, he asked June about her diet, medications and dosages, activity level, and weight gain and recorded her responses in her medical chart. Next, he instructed June to make a follow-up appointment at the Clinic for the same day next week so clinical staff could see how well she had been managing her GD. It was 11:30 a.m. and June hurried out of the Clinic to catch the bus to work.

A week later, June returned to the Clinic at 1:00 p.m. for her first follow-up appointment and reported in to the receptionist. She told June to sign her name on a clipboard located on the counter and leave her One Touch Ultra meter. The receptionist wrote June's name on a post-it note, attached it to the meter, and placed it next to two other meters on the counter. The dietician called June into her office shortly after she had taken a seat in the waiting room.

June was instructed to get on the scale and the dietician recorded her weight, as she had done the week before, and declared that June had gained a good amount. The dietician reviewed June's meal plan and food diary and asked if she had any questions about food selection. June stated that she missed eating Frosted Flakes but would give them up until after delivery. The dietician laughed and ended their meeting, which lasted five minutes. The nurse called on June as she walked out of the dietician's office.

The nurse asked June for her blood glucose logbook so they could review it together. The nurse already had a computer printout of the values, which the receptionist had downloaded from June's One Touch Ultra meter. June had maintained close to normal blood glucose levels except for one day when the values were low. The nurse asked why this had happened and June admitted she had

missed a meal while working a double-shift. The nurse was sympathetic and asked June to speak with her employer about reducing her workload. The nurse reviewed her prescriptions and encouraged her to ask questions.

First, June asked if swimming was too strenuous an activity for a pregnant woman to participate in but the nurse assured her that moderate exercise was beneficial in controlling blood glucose levels. Second, June explained that she was concerned over the pinpoint bruises she was developing on her fingers from testing her blood sugar four times a day. June said that the pain was beginning to make it difficult for her to perform everyday tasks, such as wash the dishes. In response to this concern, the nurse assured June that the bruising would fade and then showed her other locations on her body, like her thigh, where she could draw blood to test her glucose levels. Their appointment concluded after five minutes and June helped herself to a coffee and muffin while waiting for the physician.

While June waited, the nurse and dietician completed their comments in her medical chart for the doctor to review before her appointment. June was happy to see Barb when she entered the waiting room. They talked about the previous week and the difficulties and successes they had managing their GD. Barb explained that clinical staff had recommended that she use insulin to help control her blood glucose levels. June was shocked and felt sorry for Barb. Barb said that during her appointment with the nurse she reiterated her concern over having to inject insulin. The nurse acknowledged her fear and provided Barb with another demonstration on how to administer insulin properly. Barb said that she felt more confident injecting insulin after this demonstration.

After approximately ten minutes, June's physician appeared and invited her into one of the examining rooms. June said, "Good-bye" to Barb and followed the doctor down the hall. He initiated small talk while he took and recorded her blood pressure and measured her belly. Next, he reviewed her meal plan, medications, weight gain, and activity level and praised June's efforts to swim once a week and encouraged her to walk daily. He inquired about June's low blood glucose levels for the one day and she explained how her work schedule had interfered with her meals. Throughout their consultation, her doctor reiterated the importance of complying with the recommended management plan provided to her by clinical staff. Her told

June that she was managing her GD well, and therefore she did not have to come back to the Clinic for her next follow-up appointment for another two weeks. June was relieved that she was successfully managing her GD and was happy with the praise she had received from the clinical staff.

June's story provides the bulk of the context in which to understand the ethnographic space, or contact zone, where this research took place. The narrativisation of June's experiences and observations during the gestational diabetes class and follow-up appointment, as well as her interactions with staff and other patients, gives the reader a clear picture of the contact zone. In addition, the narrative reveals aspects of how the biomedical model conceptualizes GD, which will be discussed in-depth in Chapters 3 through 6. The next section fills in the remaining gaps needed to fully comprehend the ethnographic setting by describing the history of the Clinic, the key players involved, and recent changes to its services and location.

## The Clinic and its Key Players

The Clinic at the Prairie Hospital officially opened its doors in May 1987. In the years of planning before its opening, a proposal was drafted by Dr. Jones, the current Medical Director of the Clinic, and Karen Smith, R.N<sup>6</sup>. In July 1986, the final draft of the Diabetes Outpatient Program Proposal was submitted to the Department of Hospitals and accepted by the Prairie Hospital Diabetic Committee and Medical Advisory Board.

The Clinic and its mandate of patient education is structured around a multidisciplinary team of experts. There are a variety of health care professionals who provide services to the Clinic. Dr. Jones is the Medical Director and offers clinical direction to the Clinical Coordinator and is ultimately accountable to the Manager of Internal Medicine. In addition to his role as Medical Director, Dr. Jones actively consults with patients along with two other physicians practicing at the Clinic. There are an additional two doctors who consult with patients at the Clinic when the regular clinicians are absent on vacation or at conferences. The Clinical

<sup>&</sup>lt;sup>6</sup> I have used pseudonyms for all individuals presented in this research to maintain participant anonymity.

Coordinator, who is also a Diabetes Nurse Educator and advises patients, oversees the nurses and dieticians. In total, there are two nurses and three dieticians who rotate shifts at the Clinic. One nurse and dietician are employed fulltime, while the other nurse occupies a 0.8 time position and the other two dieticians occupy a 0.8 and 0.5 position. One fulltime receptionist is employed to work at the front desk of the Clinic to field questions, set up appointments, develop patients' medical charts, and maintain patient records.

Other health professionals in various departments of the Prairie Hospital, such as pharmacists, physiotherapists, and social workers, provide additional support to the Clinic by offering specialized courses to patients, like foot therapy, drug interactions, and stress management (Diabetes Outpatient Program Final Proposal 1986). In addition, there is a permanent Cantonese/Vietnamese translator employed by the hospital and a Coordinator of Multicultural Services who provides information and in-services on culturally appropriate care to clinical staff upon request.

It is interesting to note that operations at the Clinic were undergoing changes at the end of this research project. The Clinical Director informed me that the new services were to be implemented in June 2003 and explained:

The regional diabetes services are coming into play and most of the clinics in the city will be up on it... There won't be classes. There will be one core program, which is three hours in length, and then out of that core program, there are four different modules that the patient can attend or that we can put them into to better meet their needs, I guess. So, they won't be staying for three or four days if all they really need to do is adjust their insulin. So, they'll go into the insulin adjustment class.

So, it's trying to make things more efficient and more catered to individual needs?

Exactly. Trying to really improve on the wait list. [It has] actually been a mandate from the Regional Director to do something about the wait list. Basically, a complete change but the pregnancy clinic won't change at this time. They're going to be looking at the pregnancy clinics in the next phase but that probably won't happen until the fall.

Okay. So, you are quite happy with the changes then that are proposed?

Yes. It's certainly going to be very challenging. The booking and everything is going to be done differently, and there's a lot of things but it's time to make a change and it's a massive change because every place in the whole region is going to be doing the same thing. But, some of the really good things are that all the teaching materials are going to be standardized, we'll all be teaching the same thing whether you go here or the College Hospital or the Edmonton City Hospital, you'll get the same information<sup>7</sup>. So those things are really good. I think it will be great probably six months down the line when it's all up and running. Yes, we're looking forward to the change actually (LAW Interview 04/08/03).

In addition to these changes, the Clinic was relocated in December 2003 to another building on the premises of the Prairie Hospital because the hospital required more beds for patients due to an unusually severe flu season.

The previous description of the Clinic, including the narrativisation of June, Barb, and Lydia's experiences, as well as the Clinic's history and staff composition, was provided to give the reader a sense of the ethnographic setting of this research. In addition, this information is crucial to my discussion of the Clinic in relation to its conceptualization of GD, its teaching methods, and its efficacy in transmitting knowledge about GD to women, which is provided in the following chapters.

## Problematic Nature of Defining 'Asian immigrant' Women

Before outlining the organization of this thesis, it is important to address the problematic nature of defining one of the stakeholder groups who participated in this study as 'Asian immigrant' women. Several scholars reject the notion of labelling people based on ancestry and any attempt to study people based on this demarcation. As such, the use of the term 'community' may better reflect the characteristics of this group. Traditionally, the concept of community represents features such as relative homogeneity, stability, and a sense of belonging with the group maintaining well-defined geographic, political and socio-economic boundaries. However, the term community has become increasingly ambiguous in regards to defining a group of people. In this research project, for instance, the process of

<sup>&</sup>lt;sup>7</sup> I have changed the original names of the hospitals used in this quote to maintain participant anonymity.

immigration itself makes it difficult to provide specific criterion for defining the research group. Women in this study may come from various socio-economic positions, may have lived in diverse regions of China or Southeast Asia, and may speak different dialects. However, for the purposes of this research, these women share common experiences in engaging the biomedical institution as outsiders. Indeed, the terms and categorizations are problematic but do not negate the necessity to understand the experiences of these women in relation to their health.

### Thesis Organization

Chapter 2 provides the theoretical context of this research and the methods used in the collection of data. The theoretical model was derived from a combination of interpretative and applied anthropology including the use of Kleinman's (1980) Explanatory Models (EMs) Framework. The latter centres on the premise that all activities and interactions related to health, illness, and healing constitute a distinct cultural system and that better medical management can be achieved when both patients' and professionals' EMs are identified and understood.

Next, I detail the techniques I used in the collection of data for this research. I conducted seven long, semi-structured interviews with individuals from the three stakeholder groups, with the goal to elicit their understandings, interpretations, and explanations of GD. The interview prompts I developed were based on questions proposed by Kleinman (1980) for eliciting individuals' EMs. These prompts focused on what participants called the problem, how they described processes in the body, what concerned them most, and what they expected from treatment. Also, I include in Chapter 2 a discussion of how the process of obtaining formal ethics approval intimately influenced the actual methods I utilized.

The presentation of data collected during this study is divided into three chapters based on three main themes represented in the EMs framework: the problem, its process, and the stakeholders' fears. Chapter 3, "Problem", details how the various stakeholders described the problem, including what they labelled it, what they believed caused the condition, and why they thought it started when it did. Chapter 4, "Process", describes the informants' explanations of how GD worked in the body, the seriousness of the condition, and how long they expected it to last.

Chapter 5, "Fear", presents what the informants said they feared most about the condition, including the problems it caused them and their opinions and desires regarding appropriate and recommended treatments. In addition, at the end of each chapter, I discuss the potential influences from the perspectives of the Biomedical model and TCM on the explanatory models of the Asian women who spoke with me. Taken together, these three chapters provide a comprehensive comparison of the explanatory models of GD from the three sets of stakeholders.

Chapter 6 provides a summary of the three stakeholder groups' models of GD as demonstrated by the data. The goal is to highlight and explicate the differences and similarities in the conceptualizations of GD among the three stakeholder groups. I discuss how the similarities and differences in the EMs of GD between Biomedicine and TCM can be explained based on their philosophical foundations, including their conceptualizations of the body and its processes. This exercise is crucial for exploring the implications for providing culturally appropriate treatment and prevention programs to Asian women, including other diverse populations.

In addition, I address problems in the Clinic in relation to the limitations of the linear model of patient education in providing effective treatment programs for Asian women. Topics discussed include communication and language barriers as well as the notion that compliance is a culturally patterned activity, which can lead to misguided assumptions by clinical staff.

In Chapter 7, "Conclusion", I summarize the major findings of this research. In response to the initial request of the Clinic's staff, I provide guidelines for biomedical professionals working with Asian immigrant women in the management of GD. I also discuss implications of the ethics approval process for clinically based anthropological research and indicate areas for future study.

"I think it's a culture thing. It was their culture...because they have a lot of myth, I think, different ideas, Asian people" (LAW Interview with a clinician 04/03/03).

The objective of this chapter is to outline the theoretical scaffold of this research and the methods used in the collection of data. The theoretical context is derived from a combination of interpretative and applied anthropology and is specifically informed by Kleinman's (1980) Explanatory Models Framework<sup>8</sup>. The fundamental concept informing this approach is that the states of health and illness constitute a cultural system, with "...symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions" (Kleinman 1980: 24). Rivers (1927) was among the first to identify the varied experiences and practices related to health and illness as a social process and he proposed that medical systems had to be analyzed in social and cultural terms. Many researchers have embraced this approach, including Kleinman (1980), Comaroff (1988), as well as Lock and Gordon (1988).

Along with others, Kleinman has explicated how health and illness must be conceptualized and analyzed as a 'special cultural system', in the same way language, religion, and kinship are examined (1980: 30). Our worldviews impart meaning to and guide the plethora of daily activities and interactions we participate in whether these events are mundane, sacred, deliberate, and/or unconscious. This, of course, includes our interpretations of and reactions to health, illness, and medical advice and treatment options. Some examples within this cultural system include (1) health promotion, like taking a multi-vitamin or getting enough rest; (2) illness prevention, including washing your hands; (3) self-treatment, like eating your mom's chicken noodle soup for a bad flu, consulting the internet, or asking your dad if it is baking soda or baking powder you put in the bath water to ease the irritation of hives; (4) seeking treatment by engaging in an institutionalized medical system, such as Biomedicine, Traditional Chinese Medicine (TCM), Auyervedic Medicine, or less

<sup>&</sup>lt;sup>8</sup> While this framework is very familiar to anthropologists specializing in health issues, it is likely to be less familiar to biomedical professionals who constitute one of the anticipated audiences for this thesis.

formalized traditions, such as herbalism or massage therapy; and (5) evaluating treatment, such as the efficacy of the antibiotics you took or how friendly your pharmacist was when giving you assistance to determine if you will go back. These activities and interactions, among others, are evidence of the complex and diverse cultural influences on health and healing.

One way to peel back the layers of this complex system in order to understand how culture saturates every element of health and illness is to examine how various individuals conceptualize a certain condition that they define as a health issue. Gestational diabetes (GD) is an obvious candidate for such an analysis. My objective is to identify, describe, and discuss GD from the perspectives of the three stakeholder groups that intersect within the contact zone of the Clinic.

## **Explanatory Models Framework**

Kleinman coined the term 'explanatory models' (EMs) and defined them as the interpretative "...notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (1980: 105). This includes both patients and practitioners. Beginning with childhood socialization and, in the case of biomedical professionals, continuing into formal training, these models are learned and internalized over time and continue to take shape with every illness episode and experience. According to Kleinman, EMs answer five essential questions:

- 1. Etiology or cause of the condition
- 2. Timing and mode of onset of symptoms
- 3. Pathophysiological processes
- 4. Natural history and severity of the condition
- 5. Appropriate treatment options

Depending on how well a person's EM can answer the preceding questions and provide meaning to a particular illness episode, their models are reinforced, rejected, or, more likely, modified.

Kleinman's (1980) EMs Framework has been employed by numerous researchers to address a variety of current cultural issues in health. One of the best-known accounts is given by Fadiman (1997), a journalist who documented the interactions between biomedical doctors and a Hmong family in the treatment of

their daughter, Lia, who suffered from what clinicians labelled as epilepsy, but which her family determined to be soul-loss instigated by a sudden fright. Fadiman documented the devastating affects when the two cultural systems of knowledge collided in the definition of Lia's condition and its meaning, its cause, timing, and severity, as well as the appropriate modes of therapy and desired outcomes. This account demonstrated how the EMs Framework serves to "...provide both accurate phenomenological accounts of the way sickness is experienced in different cultural settings and valid hermeneutic accounts of divergent and perhaps conflicting interpretations of sickness" (Kleinman 1980: 18).

Other researchers have used the EMs approach to address topics such as HIV (Hodgson 2000), bronchitis (Snell et al 2002), child growth (Reifsnider et al 2000), psychosis (Sathyaseelan et al 2003), violence (Palinkas et al 2003), disability (Daley and Weisner 2003), asthma (Peterson et al 2002), depression (Schreiber and Hartrick 2002), and anorexia nervosa (Penas-Lledo et al 2002). In addition, several recent articles on Type II diabetes have explored variance in the attitudes, expectations, and understandings between practitioners and lay people living with the condition (Loewe and Freeman 2000; Larme and Pugh 1998; and Cohen et al 1994). However, none of the EM's literature has addressed GD.

Employing Kleinman's approach and eliciting the EMs of patients and professionals dealing with GD provides an "…interpretative method to mediate between different systems of 'medical' knowledge" (Kleinman 1980: 84). I examine the condition of GD as something that occurs within the Diabetes Outpatient Clinic, which constitutes the target of study as the ethnographic setting. The diagnosis of the condition, GD, which is experienced by women who are from Asian cultural settings but live in Edmonton and employ the services of biomedical professionals, provides the thread between the EMs of the three stakeholder groups.

Even though all individuals involved at the Clinic utilize EMs to provide meaning to any health issue, including GD, the articulation of models can differ significantly between patients and healers and are influenced by education, gender, and socio-economic status. The divergent models of patients and clinical staff can be explained based on the normative rules of each group, either popular or

<sup>&</sup>lt;sup>9</sup> The Diabetes Outpatient Clinic will be referred to as 'the Clinic' for simplicity.

professional, because EMs are "...anchored in the different explanatory systems and social structural arrangements comprising the separate sectors (and subsectors) of local health care systems" (Kleinman 1980: 73).

Kleinman has identified several characteristics that typically define patients' and clinicians' EMs. Biomedical practitioners' EMs are influenced by their training and focus on 'disease', or the pathological entity determined to cause the condition. They tend to answer all five questions in their evaluation of a condition, including cause, timing and mode of symptoms, pathophysiology, natural course and severity, and appropriate treatment options. In answering these questions, health practitioners' EMs tend to be very specific. In contrast, patients' EMs usually focus on 'illness', or the social interpretation of a condition as a lived experience. They may focus only on the questions that concern them most, including the management of symptoms and when the condition will end. Kleinman has stated, "Vagueness, multiplicity of meanings, frequent change, and lack of sharp boundaries between ideas and experiences are characteristic of lay EMs" (1980: 107, abbreviation is part of the original quote). In a more recent article, Snell et al state, "The patient model, which is often drawn from cultural traditions and norms and may not be fully articulated, tends to be less abstract, possibly inconsistent, and even selfcontradictory" (2002: 2). The table below illustrates the characteristics typical of patient and practitioner EMs:

Table 1: Differing Characteristics between Patient and Practitioner Explanatory Models

Patient Explanatory Model	Practitioner Explanatory Model
- Focus on illness	- Focus on disease
- Vague	- Specific
- Dynamic	- Static
- Ambiguous/Diffused	- Specific/Institutionalized

Based on this classification, it is important to address the danger of categorizing patient EMs as *belief* as opposed to professional EMs indicating expert *knowledge* when employing this framework. Good (1994) explicates how medical understanding is often perceived as truth because, as a model of knowledge, it is

considered to be scientific based on objective experimentation and deemed as factual. In contrast, lay models of understanding can be mistakenly perceived as constituting belief, which is defined as irrational or illogical because it is not empirically grounded. Building on the earlier work of Evans-Pritchard (1976), Good demonstrates that medical knowledge and lay knowledge are both based in cultural, historical, and political contexts and that each model of knowledge is rational, logical, and therefore, valid.

Several researchers have addressed the danger in defining a patient's conceptualizations of a condition as belief as opposed to professional knowledge, thereby perpetuating existing power structures (Young 1982 and Taussig 1980). It has been argued that Kleinman's EMs Framework may act to reproduce and replicate the power structures that exist in the medical setting by overlooking the role of power in the dyadic relationship between doctor and patient (Young 1982; Taussig 1980; and Young Leslie 2001). Alan Young stated that this approach "...becomes an instrument for co-opting and then subordinating the patient's definition, for leaving his socialized knowledge out in the cold in the form of prototypes and chain complexes, and for wresting control out of his hands" (1982: 276). In addition, Taussig (1980) argued that by using ethnographic techniques to elicit patient EMs, physicians might coax the patient to comply with biomedical intervention while appearing to be sympathetic to the patient's experience of illness. This is a problem in situations wherein the illness itself is a result of social or structural relations of inequity or of cultural differences; the physician becomes a tool enforcing the status quo rather than one that disrupts the hegemonic forces contributing to the illness experience. In their discussion of using EMs to understand diabetes, Loewe and Freeman state, "While research on diabetic patients can help bridge this gap, a one-sided emphasis on patient experience and belief presupposes a one-sided model of care in which the physician monopolizes knowledge of the other (i.e., the patient) and uses it to wrestle or cajole [her] into a more compliant state" (2000: 395).

However, the power structures Young and Taussig claim have been ignored by Kleinman's framework are learned and embodied in daily habitus. Social theorist Bourdieu defined habitus as "...an acquired system of generative schemes objectively

adjusted to the particular conditions in which it is constituted" (1990: 95). Richard Jenkins explains:

[T]he practical taxonomies of the habitus, are imprinted and encoded in a socialising or learning process which commences during early childhood. This differentiation between learning and socialization is important: the habitus is inculcated as much, if not more, by experience as by explicit teaching (2002: 75-76).

In other words, habitus provides individuals with ways to interpret the world and improvise in new situations and is embedded in real human beings and their interactions, including those between patients and practitioners. The disproportionate power relations that exist in the Clinic, between the women and clinical staff, constitute certain aspects of their EMs and it is fundamental to recognize and examine how power structures are encoded in daily habitus and impact the experiences of health and illness. Kleinman's framework is particularly relevant to immigrant health care, even if his approach is not counter-hegemonic. Leninger's (1999) transcultural nursing text documents how some cultural groups defer to experts and demonstrate high degrees of compliance with health care professionals' advice both in their home countries and aboard, as a social norm. Eliciting EMs of GD among the three stakeholder groups in Edmonton can illuminate other issues, such as access and ability to follow treatment recommendations, culturally, socially, and economically, where non-compliance and resistance to biomedical regimes may not be a paramount concern.

In addition, until recently, most of the literature has focused on the EMs of patients rather than physicians (Loewe and Freeman 2000). While physicians have authored illness narratives, the focus of such accounts has been on their role reversal to that of patients. Kleinman has noted, "The ethnography of the physician's care lags far behind the phenomenological description of the experience of illness. We know much more about the patient than the healer" (1988: 210). In Loewe and Freeman's study of the EMs of Type II diabetes of patients and care givers, they state, "...researchers continue to invoke the mantra of the 'medical model', an abstract or hypostatised image of medicine which has little to do with the way physicians practice their craft" (2000: 380). It is clear that health professionals and their clientele must all be allowed the opportunity to voice their EMs.

This research project addresses this issue by eliciting the EMs of GD among several expert groups: Asian women who have lived with the condition, biomedical health professionals, and a doctor of TCM. A comparison of EMs between patients and practitioners is essential in providing insight to clinical problems because the "…interaction between [explanatory models] of patients and practitioners is a central component of health care" (Kleinman 1980: 105). Loewe and Freeman state:

In contrast, a research agenda that takes into consideration physician experiences and feelings not only presupposes a more dialogical model of care, but can be used to promote self-reflection on the part of the practitioner. It may also, finally, allow us to move beyond the abstraction of the medical model..." (2000: 395-396).

Eliciting the EMs of Asian women with GD will document their understandings of the condition and identify their ability to access health care and effectively manage GD. Also, the EMs Framework provides these women with a voice concerning their health care, which is often lacking among marginalized, immigrant groups. As well, eliciting the EMs of the clinical staff who assists this group will record their experiences, both satisfying and frustrating, in providing health care, which is currently missing in the literature. This serves to provide practitioners with the opportunity to reflect on their interactions with Asian women and how they deliver health care. The goal of this research is to highlight the differences and similarities between the stakeholder groups and explore the implications for providing culturally appropriate treatment and prevention programs to a diverse population.

By using the EMs framework, my aim is to act as a broker between these women and the clinical staff who serve them in order to initiate dialog. This approach is less hegemonic because it is not about clinical staff figuring out what to tell women in order to achieve compliance. It is about generating dialog and giving women a voice in the Clinic, which allows them to engage with clinical staff in a negotiation of EMs. In addition, my goal is to demonstrate to clinical staff, through the presentation of my findings, that Biomedicine is a culturally constructed system of health and healing. This relates back to the quote by a staff member of the Clinic that I provided at the beginning of this chapter:

I think it's a culture thing. It was their culture...because they have a lot of myth, I think, different ideas, Asian people (LAW Interview with a clinician 04/03/03).

Eliciting the conceptualizatons of GD from the three stakeholder groups and providing this information to the Clinic will act as an exercise for them in understanding the cultural construction of their understandings of GD and of Biomedicine.

In addition to providing a theoretical context for this study, Kleinman (1980) has also articulated methods for the data collection process. These are outlined in the next section.

## Methodology

This research constitutes an exploratory qualitative methods study on the conceptualizations of GD from the viewpoint of three expert groups in Edmonton. From November 2002 to April 2003, I conducted long, semi-structured interviews with the various stakeholders. I interviewed three Asian immigrant women who experienced the condition and had used the services of a diabetes outpatient clinic in Edmonton. The interviews were conducted at their homes, ranged in length from 25 minutes to 99 minutes, and the use of an interpreter was required for two meetings. I also interviewed a doctor of TCM who practiced in Edmonton and consulted with pregnant women, among other clientele. This meeting took place at her office and lasted 45 minutes. Finally, I interviewed three health care professionals working at the Clinic, including a dietician, nurse, and the Clinical Director, who is also a nurse. All three sessions took place in their offices at the Clinic and ranged in length from 35 to 45 minutes. The following section details the data collection methods I used for this research and discusses how the ethics approval process intimately affected the techniques I chose and, subsequently, the data derived.

#### **Ethics Approval Process**

Ultimately, the methods I used for data collection emerged dialectically from the ethics approval process. Because this research was conducted as a requirement for completion of a graduate degree in Anthropology and because the locus of research took place at the Clinic of a regional hospital, it was necessary to obtain approval from two separate ethics review boards: the Health Research Ethics Board of the Capital Health Authority (see Appendix 1) and the Department of Anthropology Ethics Advisory Board at the University of Alberta (see Appendix 2). The Capital Health Region of Edmonton established the Health Research Ethics Board (HREB) in 1997 in "...an effort to improve the ethics review process for all faculty, staff, and students of the University of Alberta Health Sciences Faculties, the Capital Health Authority (CHA), and the Caritas Health Group" (HREB 2004). The HREB is divided into two panels: Panel A reviews biomedical research that is invasive and Panel B reviews non-invasive health research, including interviews, audio recording, and observation. As such, I applied to Panel B.

The Department of Anthropology Ethics Advisory Group (DAEAG) is an internal body that reviews proposed research with human subjects. Once accepted, proposals are submitted to the Faculty of Arts Research Ethics Board for final approval. Current university-based research must conform to Tri-Council Policy guidelines, which are an attempt to establish a universal set of criteria. These guidelines are intended to protect research subjects by guaranteeing anonymity, respect for human dignity and informed consent, as well as minimizing harm and maximizing benefits for participants.

The two ethics boards, HREB and DAEAG, stipulated revisions to my research methods before granting approval. First, I requested the opportunity to conduct participant observation at the Clinic, including the potential to "...engage in casual discussions with women in the waiting room". The HREB and DAEAG stated "...casual discussions with women in the waiting area could seem threatening and invasive to the women". Second, after consultation with the Medical Director of the Clinic, I requested that the women's physician, nurse, or the receptionist inform potential interviewees of the research, including the voluntary nature of participation. The Medical Director agreed that this was permissible and in keeping with the standard of research practices at the Clinic at the Prairie Hospital. The DAEAG responded that, "...an immigrant support group should act as an intermediary to provide a better introduction to the student and the project". Third, I had to address the reason why ethnic women were needed for this study and to acknowledge the

possibility that, "...just being an immigrant could make women vulnerable, which could lead to research exploitation".

These stipulations dramatically influenced the data collection techniques used in this research. First, the traditional tool of participant observation was unavailable to me due to concerns surrounding my presence in the waiting area of the Clinic. Second, and perhaps more devastating, recruitment of participants through myself or clinical staff was disallowed because of assumptions that immigrant women themselves would feel disadvantaged in terms of power vis-à-vis their treatment and, therefore, feel coerced into participating in the study.

Anthropology prides itself on its ethical stance vis-à-vis research participants. However, in the case of this research, both ethics boards failed to recognize the special quality of the relationship between ethnographer and research interlocutor, specifically, the power of the research participant to control the interview and the data collection process. The guidelines in both cases were heavily influenced by research paradigms involving experimentation, blind studies, and even misdirection, techniques rarely accepted in anthropological protocols. The methods of qualitative research employed and the process of ethics approval were intimately intertwined, and in some ways, the ethics review became part of the data collection process, inso-far as it provided insights into public (mis)perceptions of immigrant women as intrinsically vulnerable and powerless.

## Mitigation of Limitations

To preclude any potential coercion, I recruited the services of an interpreter employed by the Prairie Hospital to act as my gatekeeper, informing potential participants of this research, in Cantonese or Mandarin, and brokering connections between them and myself. In addition, informational posters and brochures, outlining the objectives of the research as well as the expectations and rights of informants, were placed in the Clinic to enable interested participants to contact me voluntarily (Appendices 3 and 4). Centralized Interpretive Services translated the documents into Chinese characters and a second independent interpreter translated the Chinese versions back into English to ensure accuracy. In addition, to alleviate

potential sources of power, coercion, or stress, each participant was interviewed in the place and language of her choice.

I commenced fieldwork in November 2002. Ultimately, the posters and brochures did not generate any interest and the unpaid interpreter failed to commit a significant amount of time towards recruiting Asian women. After four months, only two women agreed to be interviewed (and I began to panic). In another attempt to recruit interviewees, I met with a Multicultural Health Broker at the Edmonton Mennonite Centre for Newcomers. I explained my research to the broker who told me she knew a woman who might be interested in participating. The broker contacted this woman and explained the purpose of the study, the voluntary nature of participation, issues of confidentiality, and her rights as a participant. The woman consented to an interview. Though she used the services of a different diabetes outpatient clinic, I felt it was relevant and worthwhile to conduct the interview. The research questions were focused on Asian immigrant women and health professionals EMs'. While the Prairie Hospital was central to this research, this was a function of that staffs' initial identification of the problem. Therefore, it seemed an outside interview would only augment my intention of gaining a rich and detailed understanding of the conceptualizations of GD from women who were Asian and immigrants.

After six months of fieldwork and only three interviews completed, it was obvious that the advocated means for recruiting informants were inadequate. Given the limitations imposed by the ethics boards in contacting potential participants, and given the fact that the translator could not act as a fulltime intermediary, I tried to explore Asian women's understandings of GD in an alternate context by conducting multiple interviews with my first informant.

Multiple interviews with a single informant have a long tradition in ethnographic research. I hoped to build a 'detailed birthing career' narrative and to establish enough rapport with this woman to expand on the interesting insights she offered during our initial interview. The translator contacted my first informant and she consented to four more interviews, each approximately 30 minutes in length. Unfortunately, as the date of our second interview approached, her child became sick and she withdrew from the project.

It was apparent that my original objective to elicit a culturally specific explanatory model of GD among Asian women was not feasible due to my inability to recruit larger numbers of interviewees or develop a detailed birthing career history. I was faced with two options: scrap the entire study and find a new one or rework my project by examining other opportunities. In consultation with my supervisors, I chose the latter and decided to examine the conceptualizations of GD from the perspective of three key expert groups in Edmonton: the three Asian women I had already interviewed, a doctor of TCM, and three staff members working at the Clinic. In effect, the project morphed into something that, in retrospect, better represents the ideal of the EM model approach. By applying the same set of queries to the range of interconnected stakeholders, I found myself better able to do a comparative analysis of the models. Primarily, I used as a guideline open-ended questions developed by Kleinman (1980) to elicit the conceptualizations of GD from the three stakeholder groups<sup>10</sup>:

- 1. What do you call the problem?
- 2. What caused the problem?
- 3. Why did it start when it did?
- 4. Would this have happened in your home country?
- 5. How does it work in the body?
- 6. Is it severe and when will it end?
- 7. Are there any risk factors associated with the development of the condition?
- 8. What is the greatest fear around this condition?
- 9. What problems, if any, has the condition caused you?
- 10. What treatment is appropriate and what is the desired result?

#### Methods

The methodology of this research is best characterized as 'multiple methods', an old research technique recently privileged by feminist scholars for its response to real life situations, rather than laboratory-style research (Reinharz 1992).

Anthropologists utilizing qualitative methods to collect data employ different strategies to ensure reliability and confidence, which is often referred to as the Triangulation Method (Reinharz 1992 and Smith 1981). The three methods I used consisted of an in-depth literature review, observations I made at the Clinic, and

<sup>&</sup>lt;sup>10</sup> I composed and added questions number four and seven to supplement Kleinman's original eight.

semi-directed interviews about GD with the various stakeholder whose personal or professional experience made them 'experts' (Geertz 1973).

#### Literature Review

Prior to conducting fieldwork, a literature review of immigrant health in North America was essential as this research focused, in part, on the health of ethnic women new to Canada. This provided the context in which to understand how larger socio-economic and cultural determinants can influence the health of newcomers and their abilities to access (or not access) health care services. The literature review was conducted using a number of databases, including Anthropological Literature, Medline, Web of Science, Pubmed, and Academic Search Premier. Keywords employed were 'immigrant health', 'social status and immigration', and 'immigration in Canada'. After reviewing issues related to immigrant health, I performed a literature search on the topic of GD. I focused on the perspectives of Biomedicine and TCM in relation to how these two professional models conceptualized the condition of GD, including how it was defined, diagnosed, and treated. My research was conducted using a number of databases including Medline, Web of Science, CHID, PubMed, BioMed Central, and EMBASE with key words such as 'gestational diabetes', 'diabetes and pregnancy', 'diabetes and China', and 'Chinese Medicine and diabetes'.

I completed the bulk of my literature review before conducting fieldwork in the clinical setting. However, reviewing the literature is an on-going process as new information and studies become available. Therefore, I continued to assess the literature regarding immigrant health and GD during my fieldwork, as well as the analysis and interpretation of data, in order to provide accurate and current information.

#### Observations at the Clinic

The second method I used to gather data for this research was making and recording observations at the Clinic. The hospital administration permitted me to observe a gestational diabetes class and a follow-up appointment (with the woman's

approval)<sup>11</sup>. My objective in attending the course and follow-up appointment was to familiarize myself with the Clinic, learn about how GD was described and how recommended treatments were discussed, and to see women newly diagnosed with this condition. I took detailed notes during my visits on the types of information conveyed, interactions between women and the clinical staff, questions asked by patients, examination procedures, time patients spent in the waiting room, and what women said when the staff were absent.

I visited the Clinic numerous times during my research, which provided me with the opportunity to watch and record daily activities. For example, I placed informational posters in the Clinic and returned several times to make sure they had not been taken down or damaged. In addition, the interviews I conducted with clinical staff all took place at the Clinic. During these times, I engaged in casual conversations with staff and we discussed topics like upcoming weddings or plans for the weekend. During the time I spent at the Clinic, I took detailed field notes on the physical environment, including the placement of the receptionist's desk, offices, examination rooms, classrooms, and the common kitchen available to patients and staff. I documented interactions among clinical staff, between patients and staff, and among patients themselves and recorded the types of information that were available to patients in the form of brochures and pamphlets and the languages used. These observations, experiences, and notes formed the basis for the composite characters and descriptions of the Clinic offered in Chapter 1 of this thesis.

The wealth of insights I received in those hours at the Clinic confirmed for me the value of the traditional anthropological method of spending as much time as possible in the ethnographic setting. This was something my supervisor had consistently encouraged, but which had been put on hold and limited as a formal methodology when the various ethics committees objected, and due to my own shyness as a beginning researcher. Although my observations in the Clinic were supplementary to my primary method of data collection, (the semi-structured interviews), my field notes served to situate the interviews in a particular context and were vital for interpreting the interview data.

<sup>&</sup>lt;sup>11</sup> As mentioned previously, I was not permitted to speak with immigrant women while I visited the Clinic. Therefore, the follow-up appointment I observed was with a Canadian born woman.

## Long, Semi-Structured Interviews

In adherence to classical anthropology methods of listening to our interlocutors for as long as they are willing to talk to us, and in keeping with the triangulation method for data collection, I conducted long, semi-structured interviews, consisting of open-ended questions with expert informants, between November 2002 and April 2003. The emphasis of the interviews was to allow the participants to freely discuss their perceptions surrounding GD, including what they called it, how it worked in the body, what concerns it caused, and appropriate treatment options. I utilized Kleinman's (1980) questions as a guideline and composed additional interview prompts specific to each group (see Appendices 5, 6, and 7).

The following section describes the participants I spoke with and is organized based on the three stakeholder groups. Between November 2002 and April 2003, I interviewed three Asian women who had experienced GD. The interviews were conducted at their homes, ranged in length from 25 minutes to 99 minutes, and the use of the interpreter was required for two sessions. Two of the women had used the services of the Clinic at the Prairie Hospital while the third interviewee participated in a different diabetes outpatient clinic in Edmonton. Participants selected for inclusion in this study met the following criteria:

- ,
- Diagnosed with GD and referred to a diabetes outpatient clinic
   Currently using or recently employed the services of a diabetes outpatient clinic
- 3. Emigrated to Canada from Asia
- 4. Willing to participate in and consent to an interview

The women ranged in age from 34 to 39, immigrated to Edmonton between 1992 and 2002, were married, and originated from the locales of Hong Kong, rural Vietnam, and Beijing. The first languages spoken by the interviewees were Cantonese or Mandarin and one of the women had been attending English as a Second Language course in Edmonton for the past two months. Their educational backgrounds varied from completion of Junior High and High School to a University degree in computers, all achieved in their home countries. The woman with the university degree was comfortable speaking English, whereas the others

were not. While all three women were responsible for household duties and childcare, two also worked outside of the home, supplementing the family's income, and the other looked forward to finding work when her newborn was older. Two of the women were diagnosed as 'glucose intolerant' during their first pregnancies in their home countries whereas this was the first pregnancy for the third woman. All three were diagnosed in Edmonton with GD at approximately six months pregnancy. Each woman I spoke with had already delivered their new babies vaginally before our interview, even though my inclusion criteria for participation in this study included 'currently using or recently employing a diabetes outpatient clinic'. Two women managed their GD through lifestyle changes and monitoring blood glucose levels while one woman also required insulin therapy.

In March 2003, I interviewed a doctor of TCM practicing in Edmonton. I used the Edmonton Yellow Pages, looked under 'Acupuncture', picked the first name I saw, and contacted Dr. Lau by phone<sup>12</sup>. After explaining the purpose of my research, she consented to an interview at her office; this interview lasted 45 minutes.

In 1990, Dr. Lau earned her Bachelor's Degree in TCM after five years of training in China. The main component of her education focused on Chinese medicine but included the study of Western Biomedicine, specifically diagnostic techniques and technologies. Upon receiving her degree, Dr. Lau worked as a physician at a University Hospital in China for six years. In 1996, she moved to Edmonton and successfully completed the Provincial Registration Examination for Acupuncturists in Alberta. She is a registered massage therapist, has been practicing TCM in her own clinic since 1999, and consults with women on all aspects of pregnancy, including diabetes. I would have liked the opportunity to observe a consultation between Dr. Lau and a gestational diabetic but she was not consulting with any pregnant women with diabetes at that time.

During April 2003, I interviewed three staff members working at the Clinic: a dietician, a nurse, and the Clinical Director, who is also a nurse and consults with patients. Another staff member agreed to an informal conversation but requested that it not be recorded. The three interviews ranged in length from 35 to 45 minutes

<sup>&</sup>lt;sup>12</sup> I refer to the doctor of TCM as Dr. Lau, which is a pseudonym used to maintain participant anonymity.

and all three participants chose to conduct the interviews in their offices at the Clinic.

The clinical staff I interviewed were all Caucasian, middle aged women, born in Canada, who had been working at the Clinic for the past three to eight years. Two of them spoke English and one spoke French as their first languages. All three worked in the multidisciplinary environment of the Clinic and provided patient education and follow-up consultations in the management of all forms of diabetes, including GD, and taught sections of the gestational diabetes course on a rotating basis. During the gestational diabetes course, the dietician was responsible for educating patients on appropriate food selections, serving sizes, and reading nutritional labels, as well as developing clients' individualized meal plans. Also, the dietician ensured women were gaining enough weight, meeting the nutritional requirements, and advised patients on their ability to follow their individualized meal plans and maintain normal blood glucose levels during follow-up appointments. The nurses' role during the gestational diabetes class was to educate women about GD, its potential complications for mother and child, and the importance of proper management, including exercise, diet, blood glucose monitoring, and insulin therapy. They also demonstrated how to test blood sugar with a glucose meter and insulin injection technique, when necessary. During follow-up consultations, the nurses reviewed blood glucose values with patients to determine their success in managing GD. The following table lists the sources used to compile the EMs of GD among the three stakeholder groups in Edmonton.

Table 2: Sources used in the Compilation of Explanatory Models

Biomedicine	ТСМ	Asian Women
<ul> <li>Narratives of 1 dietician and 2 nurses</li> <li>Field notes</li> <li>Observations at the Clinic</li> <li>Biomedical literature</li> </ul>	<ul> <li>Narrative of a     TCM doctor</li> <li>Field notes</li> <li>TCM literature</li> </ul>	<ul> <li>Narratives of 3 women who lived with the condition</li> <li>Field notes</li> <li>Observations at the Clinic</li> </ul>

I began the interviews with all participants of the stakeholder groups by reviewing an informational letter, providing a detailed description of the study objectives, outlining the rights of participants, and explaining how I planned to use my data (see Appendices 4 and 8). In particular, interviewees were given the opportunity to refuse to participate or to terminate their involvement at any time during the study and were assured that their identity would remain confidential. Before beginning the interview, an interview consent form was reviewed and signed (see Appendix 9). Both the informational letters and consent forms were written in English at an eighth-grade reading level and then translated into Chinese characters by Centralized Interpretive Services<sup>13</sup>. A second, independent interpreter translated the Chinese version back to English to ensure accuracy. At the start of our meetings, all participants received a written version of the informational letter, contact information, and consent form in the language of their choice.

Next, I asked the interviewees' permission to document our discussions on a digital voice recorder. I showed them the recorder and microphone and described how they worked. I explained that recording the interviews allowed me to more accurately represent their voices through detailed and direct quotes. All participants agreed to be recorded except for one staff member who also asked that I not take notes during our discussion. I did not explicitly ask this individual why she did not want our conversation to be recorded but it seemed that she was worried about confidentiality, even though I explained her rights to anonymity. I took notes immediately following our interview to capture what she said.

As the final step in documenting the interviews, I immediately transcribed the digital voice recordings to provide a textual format for systematic analysis. Due to logistics and limited resources, only the English portions of the interviews were transcribed.

#### **Data Analysis**

In an exploratory study such as this one, the goal of data analysis is to educe themes to organize the data into a manageable form and to provide a framework for interpretation (Creswell 1994). To accomplish this objective, I began by reading all

<sup>&</sup>lt;sup>13</sup> The Chinese versions are included with the English versions provided in Appendices 4 and 9.

the transcripts and my field notes numerous times and began jotting down themes, categories, ideas, and observations as they emerged. This activity refreshed my memory of interviews that had occurred months before and allowed me to conceptualize my data as a whole, rather than as distinct units. During this process, it was not necessary for me to utilize qualitative analysis software, such as Atlas Ti, to code my data because the number of transcribed pages produced from the seven interviews was manageable to review by hand and this process felt more personal.

Next, I re-read the transcripts and engaged the data by focusing on the interviewees' responses related to Kleinman's (1980) guiding questions. With this process, I began to piece together the conceptualizations of GD among the three sets of stakeholders. At times, I was able to categorize the data based on responses to explicit questions I asked regarding their EMs. At other times, the EMs took shape implicitly, as the participants directed what they wanted to talk about during our interviews. In addition, I examined the clinical staff's interviews to derive what they believed Asian women understood about GD. From my analysis of the data, three themes emerged: Problem, Process, and Fear. These themes are detailed in Chapters 3 to 5.

#### Representation of Data

The data collected during this research is presented in the following three chapters based on the themes of Problem, Process, and Fear, guided by Kleinman's (1980) EMs Framework. The way in which I chose to represent the data is considered here. My main objective was to equally represent the conceptualizations of GD elicited from the three stakeholder groups. By separating the data according to three central themes, it was easy to identify the differences and similarities between and within each expert group's EMs.

The theme, Problem, details how participants labelled and defined the condition, including what caused it, why it started when it did, and if this would have happened in the Asian women's home countries. The second theme, Process, outlines how the interviewees described the mechanics of GD, including what it did to the body, what it could do, and how severe it was. Finally the third theme, Fear,

sketches what the three stakeholder groups most worried about, including what problems GD had caused and what types of treatments and results were expected.

In my representation of the data, I summarized the participants' responses to the questions to avoid redundancy where appropriate. I selected specific excerpts from the narratives, which I believed successfully demonstrated the main points expressed by the individuals in the group. However, all variability was described when participants differed in their responses to the questions so that I was certain to maintain the integrity of each person's voice and experience. In order to guarantee anonymity, pseudonyms were used for all informants.

In addition, I had to select a presentation order for the narratives of the stakeholder groups. Originally, I was going to present the narratives of the Asian women I interviewed first because their experiences of GD is not available in the literature, especially in comparison to the disproportionate amount available on the biomedical and TCM perspective of this condition. I felt that this representation would maintain the power of their voices in contrast to the well-established canons of Biomedicine and TCM. However, upon reflection, it seemed more in keeping with the goals of balanced representation to order the conceptualizations of GD in following fashion: the biomedical perspective, the TCM perspective, and finally, Asian women living with the condition. This representation of the data, which follows in the next three chapters, allowed me to compare the conceptualizations of GD among the three sets of stakeholders and has the advantage of not positioning the women's perspective in such a way that the biomedical or TCM models are privileged as knowledge, in contrast to lay belief.

This chapter outlines the conceptualizations of gestational diabetes (GD) in labelling and defining 'the problem' as told to me by the participants in the three stakeholder groups. In addition to the narratives of the interviewees, the explanatory models (EMs) of GD from the perspectives of Biomedicine and Traditional Chinese Medicine (TCM) are supplemented by the available literature on diabetes for each canon. Of course, up to this point, there is no literature on the experiences of Asian immigrant women with GD. The accounts of the three women interviewed speak for themselves and provide a rich and detailed understanding of the experiences of those who have lived with the condition. After the presentation of each expert group's conceptualizations of the problem, I examine the similarities between the two medical perspectives and the Asian women's EMs of GD. Participants in each group were asked to describe the problem based on the following five interview prompts:

- 1. What do you call the problem?
- 2. What caused the problem?
- 3. Are there any risk factors related to the development of GD?
- 4. Why did it start when it did?
- 5. Would this have happened in your home country?<sup>14</sup>

## **Biomedical Perspective**

From a biomedical perspective, the problem is called 'gestational diabetes'. In the literature, GD is described as "...any degree of glucose intolerance with onset or first recognition during pregnancy" (American Diabetes Association 2000: 1). A woman diagnosed with GD may have been diabetic previous to conception but the condition may not have been detected until she was screened for it during pregnancy. Jarvis states, "Although it may seem more sensible to distinguish between the gestational diabetic woman who reverts to normal after delivery and the gestational diabetic woman who is really only a newly diagnosed diabetic patient, this distinction does not specifically influence management during the pregnancy and indeed cannot" (1994: 595). In Biomedicine, all women diagnosed with diabetes during pregnancy are labelled as gestational diabetics and treated as such.

<sup>&</sup>lt;sup>14</sup> This question was only presented to the Asian immigrant women I interviewed.

According to the biomedical literature, ten percent of diabetics have Type I diabetes, which develops in early childhood or adolescence and is characterized by an absolute deficiency in insulin production where the individual's pancreas is incapable of producing the hormone. Type II diabetes, or adult-onset diabetes, affects 90% of people with diabetes and is described as occurring later in life and is characterized by an individual's ineffective production or use of insulin (Skyler and Hirsch 2001). Within the biomedical model, GD is classified as Type II diabetes, as these women produce insulin but either do so in limited amounts or their bodies ineffectively use the insulin they produce. It is described as a metabolic disease characterized by the body's ineffective use of insulin (Skyler and Hirsch 2001).

Within the framework of Biomedicine, national statistics demonstrate that GD is diagnosed in approximately three and a half percent of all pregnancies (Canadian Diabetes Association 2004). The cause is attributed to hormonal changes and extra demands on the body due to the growth of the foetus (Dunbar 1996 and Hare and Brown 1995). One of the clinical staff I interviewed commented on the cause of GD:

[T]he hormones from the pregnancy...I'm pretty big on that 'hormone' word. And you know, I should learn that word in Chinese, I guess. But that there is a specific reason...and it's evident and it affects the way that their body is using their own insulin...it's the stress of pregnancy (LAW Interview 04/03/03).

#### She continued:

It's not really anything that they have done wrong. GD occurs because of the stress of the pregnancy and the hormones that go along with it. That's why it wasn't there at the beginning and will go away at the end, usually (LAW Interview 04/03/03).

According to the literature, the onset of GD can occur during the second or third trimester of pregnancy, when the hormonal demands as a result of pregnancy become the greatest (Dunbar 1996 and Hare and Brown 1995). One of the clinical staff commented that GD occurs at, "...usually 28 weeks or there about" (LAW Interview 04/03/03). If a woman's body cannot adjust to this demand during the 24<sup>th</sup> to 40<sup>th</sup> week of gestation, GD begins.

To further elicit the conceptualizations of GD related to the problem, I examined the biomedical literature to determine if there were any risk factors associated with the development of the condition. Seven factors were listed:

- 1. A family history of diabetes
- 2. GD in a previous pregnancy
- 3. Having had a macrosomic baby<sup>15</sup>
- 4. Being overweight or gaining too much weight during pregnancy
- 5. Having a previous stillbirth or spontaneous miscarriage
- 6. Multiparity in current pregnancy
- 7. Belonging to a high-risk ethnic group

In summary, from the perspective of Biomedicine, the problem is labelled 'gestational diabetes', is caused by hormonal stress during the second or third trimesters of pregnancy, and its onset is influenced by several risk factors.

# **Traditional Chinese Medical Perspective**

From a TCM perspective, the term used to label the problem translates to 'gestational diabetes'. I asked Dr. Lau if TCM recognized GD or glucose intolerance and she said:

Yes, we do. In Chinese medicine we have a one big, what do you call them, big part for the diabetes. It's just that we call that the diabetes...exactly like here, the diabetes. But we call it the same, same symptoms. Like thirsty, frequent urinate, and also tired or something. The whole concept just like bio-Western medicine, [the] diabetes part (LAW Interview 03/25/03).

Diabetes during pregnancy is recognized and labelled as 'gestational diabetes' in TCM as it is in Biomedicine. However, the cause of the condition is conceptualized in different terms. According to the TCM literature, GD is classified under the category of emaciation and thirst:

The causes include excess alcoholic drinking and intake of sweet and fatty food, emotional stress, and constitutional deficiency of Yin. Deficiency of Yin and excess Dryness and Heat are two aspects of its pathogenesis, and each of these can act as a precursor to the other. As a result, the body fluids of the Lung and Stomach, and the Yin Essence of the Kidney are consumed. In a protracted case, both Qi and Yin become deficient, and deficiency of Yin affects Yang, thus

<sup>&</sup>lt;sup>15</sup> The term 'macrosomic' refers to a heavy for birth weight, usually defined as over 4000 grams.

giving rise to deficiency of Kidney Yang as well (Zhong Yin and Hui De 1997: 172).

In addition, I asked Dr. Lau to tell me what caused diabetes to occur during pregnancy and she stated, "...we think that [its] because the meridian, the organ system, they are changing because the pregnancy is changing the whole body" (LAW Interview 03/25/03). Next, she elaborated on the notion of balance through the concepts of Yin and Yang and explained that GD typically resulted from a deficiency of Yin:

In Chinese medicine there's a big part, big concept is Yin and Yang, two parts. You know, for the diabetes, this kind of group of patients they belong to the Yin part is too low. So, Yin and Yang, they have to be in the balance way. So, once the Yin is too low, they will show in symptoms, the diabetes symptoms (LAW Interview 03/25/03).

In TCM, the timing for the onset of GD can occur earlier than that prescribed by Biomedicine. Dr. Lau explained that the onset of diabetes could occur at any time during pregnancy due to the disruption of balance in the body. In TCM, women are screened for GD at their first prenatal appointment and throughout their entire pregnancy. From the perspective of TCM, it is important to look for the symptoms of GD throughout the pregnancy because of the changes occurring to the woman's body during this time. In addition, the timing of GD is dependent on the woman's individual constitution. Dr. Lau stated:

That depends because the patient themselves...But when they come to the doctors in China, you know, you always try to find [GD], it doesn't matter how many weeks [gestation]. Sometimes, because [a woman] got pregnant for some certain period, they got the high blood sugar, very high. And then, later, they will go back to normal just because the body change... (LAW Interview 03/25/03).

I also asked Dr. Lau if there were any risk factors that could predict the onset of GD. She explained that high blood pressure or cholesterol as well as a family history of diabetes could be considered factors leading to an increased probability for the onset of GD. However, she reiterated the importance of the external examination in the diagnosis of the condition because its development depended on individual constitution and the body's ability to regain harmony during pregnancy.

From the perspective of TCM, the conceptualization of the problem included the labelling of the condition as 'gestational diabetes', which was caused by a deficiency or excess of Yin or Yang which disrupted balance in the body, and could occur at any time during the pregnancy due to the variability of individual constitution. The central idea behind TCM's conceptualization of the problem of GD is how disharmony affects the individual body.

# Asian Immigrant Women

Among the three Asian women I spoke to who lived with the condition and regarding their conceptualizations of the problem, Jade and Chen (from Hong Kong and Beijing, respectively) explained that they labelled their problem 'diabetes'. In contrast, Tran (from Vietnam) said, through the interpreter, "There is no term or anything to call for that because [she] hadn't heard of that in her country and until [she got pregnant] is the first time she has experienced this" (LAW Interview 02/17/03).

Next, I asked each woman to tell me what caused the condition. Jade stated that she had inherited GD from her mother, who was recently diagnosed in Hong Kong with Type II diabetes. In addition, Jade noted that her older age at conception, 39, contributed to the onset of her condition. The interpreter said, "She says it is usually the people, like [when] they [get] pregnant when they get a little bit old, like older age, they may have a chance to get diabetes" (LAW Interview 11/12/02). In contrast to Jade, Tran was uncertain as to why she developed GD: "For her, she think that maybe she eat too much sweet...But she's not sure (translator laughs)" (LAW Interview 02/17/03). Later in our interview, Tran said that her doctor explained that lack of exercise and an unhealthy diet caused her to develop diabetes during this pregnancy.

Chen's response as to what caused her to develop GD was, in part, similar to Jade's. Though Chen was diagnosed with glucose intolerance during her first pregnancy in Beijing, she stated that her older age at conception, 39, was responsible for her developing GD during her second pregnancy in Edmonton. In addition, Chen further explained that changes to her diet since arriving in Edmonton had adversely affected her blood sugar:

I think the age is important. And the food is, I think when I eat the oil more of the blood sugar is high. So after the supper, I test my blood [sugar], is high...Because the Chinese, the Chinese family in the supper food is not many. Lunch is not many...

Okay, so not so many foods?

Yes. It's simple...In China, we eat the vegetable is more. But in [Edmonton], the meat is more (LAW Interview 04/28/03).

Chen blamed her increased consumption of sugary drinks, oily foods, and meats, along with eating fewer vegetables as further contributing to the onset of her condition during this pregnancy. From our conversations, it is clear that the women considered the risk factors for GD to be things that were both within and not within their control: they considered age, heredity, lack of exercise, or an inappropriate diet as contributing factors to the onset of their GD.

To further elicit the women's conceptualization of their problem, I asked them to tell me when their condition started. Their explanations were rooted more in their own experiences of having been diagnosed with GD rather than the symptoms or causal factors. For example, Jade explained that GD started during her second pregnancy in Edmonton and elaborated that the condition did not exist before her family physician labelled her as diabetic. Jade explained that her family doctor told her it was unusual for women to develop GD before six months into the pregnancy. Indeed, all three women told me that they did not develop GD until their doctors diagnosed them as such.

I asked the women an additional question to further elicit their conceptualizations of GD: Would you have developed GD if you were still living in your home country? Jade and Tran commented that it did not matter, even though their reasons were different. Jade stated, through the translator:

If [she's a gestational diabetic], it doesn't matter in Hong Kong or Canada. If she [has] it, she still have it like that and it's normal. A lot of women in Hong Kong, they gestational diabetics" (LAW Interview 11/12/02).

Jade believed that living in Hong Kong would not have made a difference in her condition because GD is something that affects women everywhere, especially when they are older.

In contrast, Tran said through the interpreter, "It [does] not matter because she never have a pregnancy before in her country but she says even though if she has [this condition in Vietnam] it's also hard to tell whether you are gestational diabetes or not because there is no such test to find out" (LAW Interview 02/17/03). Based on Tran's statement, it would not have mattered if she were still living back home because she understood that there were no tests in Vietnam to test for GD. In contrast to Jade and Tran, Chen explained that she would not have developed GD during her second pregnancy if she were still living in Beijing:

Because, Beijing the vegetable and the food is cheap. It's very cheap. I can eat more. Here, the meat is cheap (laughs).

Right. So you feel that if you were in Beijing and you were able to eat more fruits and vegetables, maybe the GD wouldn't have been as bad?

Yes...Here the sugar, the juice, is drink more than Beijing.

Ok so you're drinking more sugary drinks that you would back at home?

Yes. I think (LAW Interview 04/28/03).

Chen believed that she would not have developed GD in her home country because her change in diet since arriving in Edmonton, as a result of economic pressures, caused her condition.

In general, the Asian women I interviewed explained that the problem was called 'diabetes'; it was caused by various factors, such as age, heredity, or diet; it was possible to get it in their home countries, but it was more likely in Canada because of the difference in diet; and it began when they were diagnosed by biomedical practitioners in Edmonton.

## Comparing Conceptualizations of the Problem

The objective of this section is to compare the biomedical and TCM perspectives of GD to the Asian women's conceptualizations of 'the problem'. Biomedicine and TCM both labelled the condition 'gestational diabetes', as did Jade

and Chen, while Tran had no name for her condition. But in general, the three stakeholder groups labelled the problem as 'gestational diabetes'.

In relation to the cause of GD, the biomedical perspective explained that it was a result of increased hormonal demands during pregnancy, while the TCM point of view determined that it resulted from an imbalance of Yin and Yang, causing disharmony in the body. The Asian women's conceptualizations did not directly relate to either of these two possible explanations. Instead, Jade explained she had inherited GD from her mother and Chen attributed the condition to her change in diet upon arriving in Edmonton. Both Jade and Chen cited their older age at conception as an additional contributing factor. In particular, Chen's answer conveyed an understanding that an imbalance related to diet, similar to that proposed by TCM, caused her condition when she stated that eating oily foods increased her blood glucose. In contrast, Tran's explanation for the cause of GD was practically non-existent except for when she said that her doctor explained to her that an unhealthy diet and lack of exercise caused her condition. In this case, the biomedical perspective of GD may have influenced Tran's EM because she attended the gestational diabetes course at the Clinic.

Biomedicine and TCM differed in their conceptualizations regarding the onset of GD. The biomedical perspective claimed the condition could occur between the 24<sup>th</sup> and 40<sup>th</sup> weeks of gestation as compared to the TCM perspective that stated GD could occur at any time during pregnancy. According to the Asian women I interviewed, GD began when their doctors in Edmonton told them they had the condition. The influence of the biomedical model was apparent when Jade said her doctor told her that it was unusual for a woman to develop GD before six months of pregnancy. The following table exhibits the similarities in the EMs of GD, as told to me by three Asian women and related to 'the problem', as compared to the conceptualizations of GD provided by Biomedicine and TCM.

Table 3: Comparing Conceptualizations of the Problem

Questions:	Jade	Chen	Tran
What is it called?	BM/TCM	BM/TCM	BM/TCM
What caused it?	Neither	TCM	BM
When did it start?	BM	BM	BM

The women's conceptualizations of the problem were more similar to the biomedical explanation than that of TCM. The probable reason for this was that all three women had participated in a gestational diabetes informational clinic and follow-up appointments with biomedical practitioners in Edmonton shortly before our interviews. In addition, the term 'gestational diabetes' does not have a strongly competing diagnostic label in TCM. The women did not articulate a localized name for the condition, such as 'sugarblood'. Their EMs surrounding 'the problem' were largely based on the information and explanations they received from staff at the Clinic.

This chapter outlined the labelling of the condition and the definitions of *the problem* offered by the three stakeholder groups. The next chapter details their understandings of GD as *a process*.

The previous chapter described how interviewees from the three stakeholder groups labelled and defined the problem of gestational diabetes (GD). This chapter details the second theme derived from the data, the process of GD or how it works in the body, as told to me by participants. As with the previous chapter, I supplemented the explanatory models of GD provided by the biomedical professionals and the doctor of Traditional Chinese Medicine (TCM) with the available literature. The final section of this chapter examines how the Asian women's conceptualizations regarding the process of the condition are similar to those represented by Biomedicine or TCM. The participants in each expert group were asked to described the process of GD based on the following two interview prompts:

- 1. How does GD work in the body?
- 2. How severe is the condition and when will it end?

## **Biomedical Perspective**

From a biomedical perspective, diabetes is described as a metabolic disease characterized by: 1) the body's inability to make insulin or adequate amounts of insulin; or 2) the ineffective utilization of insulin by the body (Skyler and Hirsch 2001). Individuals consume food in order to fuel the processes of the body. When food is digested, carbohydrates are broken down into glucose, the form of sugar useable by cells. Glucose is absorbed from the intestines into the blood stream where it travels throughout the body. The rising levels of glucose signal the pancreas to release insulin, a hormone, into the blood stream. Insulin acts like a key, which fits into the cell's insulin receptor lock. When the cell's insulin receptor is unlocked, glucose enters the cell to be utilized. Whenever an individual eats or drinks, the amount of glucose in the blood increases and the pancreas reacts by supplying more insulin to maintain stable sugar levels. If the body is unable to produce or effectively utilize insulin to 'unlock' the cell, glucose cannot enter the cell and builds up in the blood, potentially resulting in the onset of diabetes (Skyler and Hirsch 2001).

As mentioned in Chapter 3, "Problem", Biomedicine classifies GD under the category of Type II diabetes, as these pregnant women do produce insulin but in

limited amounts or their bodies ineffectively use the insulin. During pregnancy, a woman's insulin needs can increase up to three times her non-pregnant norm. If a woman's body cannot respond effectively to the increased demand for insulin to transport glucose from the bloodstream into the cells, she is considered to be in a state of glucose intolerance, or a gestational diabetic. One of the clinical staff I interviewed elaborated on the processes occurring in the body of a gestational diabetic:

[T]he main message is to understand that it's not sugar causing their high blood sugar. It's carbohydrates, okay? That's the main thing because out there people think it's sugars, "If I don't eat sugar, I'm okay. Or anything with sugar, I'm okay. But I can have my big plate of spaghetti and my bagel and a big apple and all...because this is good for me". So, it's to relate all of these foods are carbohydrates, the same thing as foods that have sugar. They are all carbohydrates. And it's taking more than what your body can handle at that particular time that will increase your blood sugar (LAW Interview 04/03/03).

According to Biomedicine, the pathophysiology of GD can be summarized as follows. Hormonal demands during pregnancy increase the woman's need for insulin. If the woman's body cannot respond effectively to this change, she becomes diabetic. Because the body is not utilizing insulin properly, ingesting large amounts of carbohydrates will significantly increase blood glucose levels.

From a biomedical point of view, GD is considered one of the most severe conditions affecting pregnancy and can lead to several complications for the mother and infant (Reece and Coustan 1988). Risks to the mother include delivery by caesarean section, a higher risk of infections, and pregnancy induced high blood pressure. Risks to the infant include macrosomia, hypoglycemia, and Respiratory Distress Syndrome (Dunbar 1996). According to Biomedicine, GD will typically cease shortly after delivery. However, both the mother and infant are at an increased risk of developing Type II diabetes later in life (Canadian Diabetes Association 2004).

## **Traditional Chinese Medical Perspective**

The TCM literature describes the physical processes of diabetes quite differently from that found in Biomedicine and centres on the notion of balance or harmony. It is necessary to review the concepts of Yin and Yang as well as Qi in order to understand how TCM conceptualizes the process of GD.

# Ying/Yang and Qi

In Chinese mythology, the creation of the universe was conceived in terms of reproduction or the union of opposites, that being male and female (Mahidhassan 1988). One of the fundamental concepts of Chinese culture and medicine, Yin and Yang, is generated from this notion of opposites. Yin represents female, earthly, inner, cold, negativity, and darkness whereas yang represents male, heavenly, outer, heat, positivity, and light (Gould-Martin 1978 and Tang 1995). Yin and yang are conceptualized as opposing yet complementary and mutually interdependent forces that control, create, and transform one and other where one cannot exist without the other (Ehling 2001).

The concept of Yin and Yang has been "...incorporated into the applied sciences, such as medicine and geography" (Tang 1995: 272). In TCM, most things are classified as having Yin or Yang attributes, including foods, herbs, body parts, diseases, and stages of life (Chen 2001; Shih 1996; and Mitchell and Mackerras 1995). An individual must maintain balance or harmony between Yin and Yang for good health.

The interplay between the forces of yin and yang create Qi or  $Chii^{16}$  (Mahdihassan 1989). Qi is defined as "...the vital energy that is behind all physiological processes" (Ehling 2001: 71)<sup>17</sup>. Based on ancient Chinese medical texts,

males and females are endowed at conception with a store of vital 'primal chi'?... inherited from heaven, which accumulates in the body through puberty, but thereafter is gradually lost through reproductive acts – particularly ejaculation in males and menstruation, childbirth, and lactation in females. Metabolic processes, supported by eating, breathing, activity, and rest, replenish and circulate the body's vital

<sup>&</sup>lt;sup>16</sup> Both terms are pronounced *chee*.

<sup>&</sup>lt;sup>17</sup> Other translations for Qi include energy-matter or life force (Ehling 2001).

forces, producing a rhythm of cyclical renewal... (Farquhar 1992: 29-30).

The notion of Qi can be difficult for Westerns to comprehend as it has no physical shape or form and is felt as a force moving through the body (Ehling 2001).

Based on the concept of Qi, TCM practitioners formulated a different geography of the body compared to Biomedicine. Ehling states:

The ancient masters traced pathways through which qi passes and located points along them at which the qi communicates with the surface of the skin...All organs are interconnected with each other by way of this meridian network system (2001: 72).

Therefore, the body is viewed as a whole where disease in one organ can affect another (Ehling 2001). TCM maintains that the basic principle working in the body is balance and within this humoral framework, disease stems from "...natural forces or conditions as cold, heat, winds, dampness, and above all, by an upset in the balance of the basic body elements" (Foster 1998). From the perspective of TCM, the body is irreducible to separate parts autonomous from one and other.

Based on this conceptualization of the body, the physiopathology of GD in TCM is explained in terms of disharmony resulting from a deficiency of Yin, which directly affects Yang.

Deficiency of Yin and excess Dryness and Heat are two aspects of its pathogenesis, and each of these can act as a precursor to the other two. As a result, the body fluids of the Lung and Stomach, and the Yin Essence of the Kidney are consumed. In a protracted case, both Qi and Yin become deficient, and deficiency of Yin affects Yang, thus giving rise to deficiency of Kidney Yang as well (Zhong Yin and Hui De 1997: 172).

Dr. Lau stated that an imbalance of Yin and Yang results from the malfunctioning of the digestive system. She compared this to biomedicine and explained, "...in diabetes, we say like digestive system is not function well. If you translate to the West medicine you can see maybe the pancreatic...you know if the function is not catching up" (LAW Interview 03/25/03).

When I asked Dr. Lau about the processes of GD in the body, she commented that it is conceptualized as the disharmony of Yin and Yang and she focused on symptoms derived from the external examination of a pregnant woman:

Once we check the pulse, that's a big part in Chinese medicine, check the pulse. And also, check the complexion, you know, see the colours exposed to you...Also [the] hair on the outside looking and also you see if some swollen around the ankles.

What does that indicate? Swelling around the ankles?

That means either the Kidney's function or Spleen's function not too strong...So when that part is weak, the body will contain extra liquid inside body because the circulation is not, not good enough to get out the extra liquid part (LAW Interview 03/25/03).

The symptoms presented provide insight into the exact processes taking place within the body, that being an excess or deficiency of Yin or Yang. The emphasis placed on particular symptoms presented by a woman draws attention to the importance TCM places on individual constitution.

Dr. Lau stated that GD is considered a severe condition affecting pregnancy and that it would typically cease shortly after delivery if the woman cared for herself properly during the postpartum period. She explained that potential complications of GD for the mother and infant were the manifestation of the symptoms of diabetes, such as feeling tired.

## Asian Immigrant Women

Of the three women I interviewed, none were certain as to how GD worked in their bodies. Jade stated, "There's nothing" while she moved her hand over her stomach indicating that she had no explanation for how the condition worked or affected her body. Chen and Tran responses were also vague but they explained the physical processes of GD in terms of symptoms. For example, Chen said:

I feel (pause) the weight is lost.

You've lost weight?

Yes and also I feel thirsty (LAW Interview 04/28/03).

Tran stated, through the interpreter, "[She doesn't] feel anything at all, like a normal feeling. She still [went] to work as usual, and after the doctor said that, is the same kind of feeling, just be more careful what [she is] eating" (LAW Interview 02/17/03). In other words, Tran kept going to work as usual and did not experience

any symptoms or changes in the way she felt even after the doctor told her about her GD. She was just more careful about what she ate. When explaining how GD worked in the body, both Chen and Tran focused on the symptoms even though one woman experienced them and the other did not.

All three women I spoke to told me that GD was a very serious condition. This was especially evident for Chen who had to take insulin in addition to making life style changes in order to manage her condition. I asked the women to tell me when they believed their GD ended or would end. Even though Tran had delivered her son approximately two months before our interview, she communicated, through the translator, "She's just the most concern[ed] that her diabetes doesn't go away after the baby is born" (LAW Interview 02/17/03), indicating she was uncertain as to when she might be cured of GD. Chen's response to this question was elicited when I asked her if she was still seeing any doctors since her delivery about her condition:

No.

No? So your blood sugar has gone back to normal?

Because I didn't make appointment with the actual doctor.

So you didn't make an appointment to go back and see the doctor but your baby is still being tested every once and awhile?

I don't know whether test his sugar...(LAW Interview 04/28/03).

Chen did not know whether she was cured of GD since delivering her baby and she did not know if her son's blood glucose levels had been checked.

Jade's response to the question, "When will your GD end?" was elicited throughout our conversation and it became evident that she had no idea if she was still diabetic, three months after delivery. Jade explained that after her son was born she was given a glucose drink by clinicians and tested two hours later to determine her blood glucose. The translator said to me, "...they test and she is nine point and she doesn't know is that high or low? She is asking me and still I don't know" (LAW)

Interview 11/12/02)<sup>18</sup>. Jade did not understand the significance of this numerical value even though she had been monitoring her blood glucose levels during her pregnancy. Later, when I asked Jade what it meant to be cured of GD, she said through the translator:

The answer and the word from the doctor is the main point. The doctor say, "You fine, you're not diabetes", she says she totally feel relaxed and everything is solved. Because like...(Jade interrupts)...if the doctor didn't tell you, you keep thinking of the ideas in your head, like you may get diabetes and why and for how long and why you get it so soon? Those questions still in your head...you can never be clear or recover and it's not treated. One word from the doctor say, "Well, you fine, you're not diabetes", and she says everything is solved (LAW Interview 11/12/02).

At the end of our interview, I asked if Jade had any questions about this research and the translator replied, "Her question is if she's gestational diabetic right now, is that she keep to see the specialist at the Diabetes Outpatient Clinic regularly? That she want to know is what she's suppose to do right now" (LAW Interview 11/12/02). In addition, Jade did not know if her newborn son was diabetic or would develop diabetes:

She was asking if she is gestational diabetic when she was pregnant with [her newborn] and she is afraid if he will be diabetic (LAW Interview 11/12/02).

Jade continued asking about me about the health of her baby and the translator said, "Her main question is the baby maybe diabetic or not? And she's not sure if they did any tests on the baby to find out the baby is diabetes or not". Based on what the three Asian women told me, it is clear that none of them knew whether they were still diabetic, if their infants were diabetic, and if or when they would be cured.

# Comparing Conceptualizations of the Process

As I did in the previous chapter, I examine the similarities between the biomedical and TCM perspectives and the Asian women's conceptualizations surrounding 'the process' of GD. Biomedicine conceptualizes GD as a metabolic

<sup>&</sup>lt;sup>18</sup> According to the biomedical literature, the normal range for blood glucose levels falls in between the numerical values of three and seven. Jade's glucose reading of nine points is considered high.

disorder that can occur during pregnancy due to a woman's inadequate production or use of insulin in transporting glucose to cells to be used for energy. In comparison, TCM conceptualizes GD as a meridian disorder that may occur during pregnancy due to an imbalance of Yin and Yang resulting in the disruption of the kidney, stomach, and spleen meridians. It is considered normal for a woman's body to experience some disharmony during the beginning of pregnancy as her body readjusts to its new state. However, the symptoms of diabetes will present if a woman's body is unable to regain balance, typically indicating a deficiency of Yin.

Neither professional model was similar to Jade's conceptualization of 'the process'. In fact, she had no explanation as to how GD worked in her body. On the other hand, the explanations provided by Chen and Tran were similar to that provided by TCM in that they focused on the symptoms of GD. Chen referred to the presence of symptoms to talk about how GD worked in her body. Tran also focused on symptoms as a means to explain the process of GD. However, since she did not experience any symptoms, she could not explain the process because she felt the same as she did before she was diagnosed with GD.

All the participants I interviewed among the three stakeholder groups stated that GD was a severe condition affecting pregnancy. However, while both Biomedicine and TCM explained that, typically, GD would go away shortly after delivery, none of the Asian women I spoke to expressed this. Most shocking were all the medical questions Jade asked me in relation to whether she and her son were diabetic and if the condition would ever go away. It was apparent from the responses provided to me by the three women that none of them were similar to the perspectives of Biomedicine or TCM in their understandings of if or when they would be cured of GD. The following table illustrates the similarities, where they exist, between the biomedical and TCM conceptualizations of the process of GD in comparison to the Asian women's EMs of their condition.

Table 4: Comparing Conceptualizations of the Process

Questions:	Jade	Chen	Tran
How does it work?	Neither	TCM	TCM
How severe is it?	BM/TCM	BM/TCM	BM/TCM
When will it end?	Neither	Neither	Neither

Although the women's conceptualizations of GD related to the process were more vague than those provided by Biomedicine and TCM, they were more similar to the EM of TCM as both these stakeholder groups focused on the symptoms of GD. The women explained that GD was a serious condition affecting pregnancy, as did Biomedicine and TCM. Neither medical model was represented by the women's EMs when it came to explaining when they would be cured of GD. While Biomedicine and TCM explained that GD would typically cease shortly after pregnancy, the women I spoke with had no idea if or when they would be cured of the condition. As was the case when explaining the 'problem', the Asian women had no localized theory for how GD worked in their bodies. The women's EMs for the process of GD was largely based on the information they received from clinical staff. This information was then re-interpreted via their Asian-influenced epistemologies of harmony, balance, and individual manifestation of symptoms.

The two previous chapters detailed the three key expert groups' conceptualizations of the first two themes: *the problem and process* of GD. The next chapter presents what interviewees told me about the final theme: *Fear*.

This chapter presents the third theme I derived from the data and guided by Kleinman's (1980) Explanatory Models (EMs) Framework. This section outlines what interviewees from the three stakeholder groups told me were their fears surrounding gestational diabetes (GD). This provides the final piece in the conceptualizations of GD from the expert groups and includes topics such as (1) fear and frustration concerning the condition, (2) problems GD caused, and (3) appropriate treatment options and desired outcomes. As I did in the previous two chapters, I supplemented the explanatory models of GD presented by the biomedical professionals and the doctor of Traditional Chinese Medicine (TCM) with the available literature. The final section of this chapter examines if the conceptualizations presented by the two medical perspectives are similar to the Asian women's understandings of GD as related to 'fear'. The EMs of GD related to fear were elicited from participants in each group based on the following three interview prompts:

- 1. What is the greatest fear around this condition?
- 2. What problems, if any, does the condition cause?
- 3. What treatment is appropriate and what is the desired result?

## **Biomedical Perspective**

From a biomedical perspective, the greatest fear related to GD was the potential health complications for the mother and foetus, which were outlined in Chapter 4, "Process". According to Biomedicine, the risks to the mother include delivery by caesarean section, a higher risk for infections, and pregnancy induced high blood pressure. For the infant, the risks include macrosomia, hypoglycemia, and Respiratory Distress Syndrome.

Although the greatest fear surrounding GD was the health complications for mother and infant, this concern was situated within the context of 'non-compliance'. The clinical staff I spoke with described the frustrations they experienced when women 'mismanaged' their condition. One staff member told me that the Clinic witnesses a high degree of compliance among all women in the management of their GD and she continued:

In general, we have fairly high degrees of compliance but then [you] still have the one that it doesn't matter. That no matter, you could see them every two weeks and you keep repeating the same thing every two weeks and there's no change and that's the one you cannot understand, especially when they're intelligent people and why can't you make this a priority...it is frustrating. When you have your people, you know, you cannot, you do not choose [your patients] but when you have the people that have low mental [capabilities], they're slower mentally, those people even will try even harder and yet this person [does not] just because she's making all kind of excuses. If she really put her foot down, she could do it. And why can't they understand? (LAW Interview 04/03/03)

In addition, while discussing the most rewarding aspects of her job, one of the clinical staff said, "If the message is getting there and the outcomes are good and in that you have control of the diabetes and, you know, normal birth weight baby and no complications" (LAW Interview 04/03/03). Another clinical staff member said that the most rewarding aspect of her job was when women came for their follow-up appointments and would say, "I feel so much better" or "You cured me" (LAW Interview 04/03/03), which indicated that treatment had been accepted and successful.

According to the clinical staff, non-compliance with the recommended treatment regime would result in their greatest fear: health complications for mother and infant. Another concern from the clinical staff's point of view was that some women did not return to the Clinic after their initial appointment. For example, one of the clinicians told me that, "...the majority of time, most women who either are unable or afraid, or don't want to, or don't understand, they just don't return. They don't do the follow-up appointments...and that's their right" (LAW Interview 04/03/03). The assumption being made was that if women did not come back to the clinic to be monitored, the management of their GD would be less than optimal and result in negative health outcomes for the mother and her baby.

Continuing to focus on the issue of compliance, clinical staff I interviewed discussed what they thought might hinder women's successful management of GD, specifically not following the treatment regime. These issues included work or school schedules and financial difficulties in buying the supplies needed to monitor blood glucose levels. One of the clinical staff stated:

If they can't afford the strips and it's frustrating because we don't, we're not able to supply the strips...they won't test because they just don't have the strips and the money to buy the strips. So that the cost of taking care of themselves, I guess, is frustrating (LAW Interview 04/08/03).

Two of the staff discussed how inflexible work schedules could make it difficult for women to follow a grazing pattern of eating and testing their blood glucose levels two hours after each meal:

Sometimes, there's a problem with the ones that are working. I don't know the flexibility for snacks sometimes is not the same, you know? So, you try to give them some ways how they could do it because I think working conditions sometimes they are not the same. A lot of them will be working in factories and stuff like this and I think it's much stricter in those places that I cannot have my break at that time and I can only do this time. And so, sometimes, then they will have some problem, those areas.

Right, but that has to do with the working situation?

Oh yes. Because yes, it has nothing to do [with the clinic]. It's their working conditions...you try to see if they can't work with the employer, you know, to make it to where it is better to do it (LAW Interview 04/03/03).

In addition, another staff member commented, "A lot of these women go to school as English as a Second Language and so even the appointment schedule is difficult sometimes because of going to school" (LAW Interview 04/03/03). From the clinical staffs' perspective, the problem was non-compliance, which would lead to poorly controlled blood glucose levels and potentially negative health outcomes for mother and infant. The preceding section described clinical staff's conceptualization of 'fear' in relation to what they feared most about the condition and the problems GD caused. To further elicit clinical staffs' conceptualization of GD in regards to 'fear', I asked them about the proper treatment for the condition and desired outcomes.

The treatment of GD has been well documented in the biomedical literature and was practiced in the clinic by the health care workers I interviewed.

Recommended treatment included diet, monitoring blood glucose levels, exercise, and in extreme cases, insulin therapy. According to the literature, approximately

two-thirds of gestational diabetics are able to successfully manage their condition with the implementation of a balanced diet. A grazing pattern style of eating with three meals and two to three snacks per day is recommended. Individualized meal plans are created for each woman to balance the intake of carbohydrates, proteins, and fats. In addition, management of GD consisted of monitoring blood glucose levels. Health care workers relied on these values to determine a woman's degree of success in managing her condition and whether the treatment plan had to be altered. Exercise was another recommendation in the successful treatment of GD resulting in lowered blood glucose levels and assisting the body's cells to become more sensitive to insulin (American Diabetes Association 1997).

From the perspective of Biomedicine, most women with GD are able to effectively manage their condition through a program of healthy meals, blood glucose monitoring, and participating in moderate exercise on a regular basis. However, if blood sugar levels remain consistently high, insulin therapy is required. Even though insulin therapy is necessary for some pregnant diabetics, biomedical practitioners agree that a treatment program focusing on healthy eating, monitoring blood sugar levels, and participating in moderate exercise is usually all that is needed for the successful treatment of gestational diabetes. The desired outcome of treatment is to maintain close to normal blood glucose levels.

## **Traditional Chinese Medical Perspective**

From a TCM perspective, Dr. Lau said that the greatest fear surrounding GD was that the mother and her baby would suffer the symptoms, including fatigue, frequent urination, and not feeling well, especially if treatment was not successful. She did not comment on any potential complications during delivery for mother or infant or a possible increase in their chances for developing diabetes later on in life. Dr. Lau explained that the biggest problem caused by the condition was living with these symptoms. Besides asking Dr. Lau about the TCM conceptualization of GD based on what was most feared about the condition and the problems it caused, I asked her to tell me about appropriate treatment options and the desired outcome.

<sup>&</sup>lt;sup>19</sup> The American Diabetes Association states that approximately fifteen percent of pregnant diabetics will need to take insulin as part of their management program (1997: 33).

According to TCM, the most appropriate means for treating GD was to use natural remedies, such as foods and herbs in order to restore the balance of Yin and Yang in the body, thereby alleviating the symptoms of the condition. Li et al (2004) lists 86 natural medicines, used in TCM and related to anti-diabetic effectiveness in both experimental and clinical trials. The identification of the symptoms experienced by a woman was crucial to providing the most effective treatment plan. In TCM, symptoms are classified into categories depending on their characteristics, which include hot, cold, dry, and/or wet. Herbs and foods are also classified based on their metabolic properties and the objective of therapy is to balance deficiencies or excesses of Yin and Yang by consuming the proper foods. For example, Dr. Lau explained:

There's four major, different area [of] herbs to treat different symptoms, different illness. There's cold, hot, cool, and warm. If the patient show very hot symptoms, feel hot, they're dry, just couldn't sleep, all symptoms showing the hot part and we will use cold herbs to compromise [or bring the body back into balance] (LAW Interview 03/25/03).

Not only does treatment depend on the specific symptoms expressed but it also depends on individual constitution and TCM places a great deal of emphasis on the variability between women's bodies.

Dr. Lau reiterated the importance of proper diagnosis of symptoms based on the individual woman. When I asked how she treated a woman with GD, she stated:

I've also checked the patient. Everybody is different. You need to see the symptoms if this is why [this treatment] is suitable for her or not for her.

So, it really depends on individual constitution?

Right. Some foods, I can take more and she couldn't take more, you know? Depends how strong is the digestive system, how strong is the body (LAW Interview 03/25/03).

In addition to individual constitution and the proper diagnosis of symptoms, awareness of the environment is important for the effective management of GD. Dr. Lau explained that for a woman living in Edmonton who was pregnant and displaying 'hot' symptoms of GD during the winter months, 'cold' foods would be

avoided because this would be too much for the body to handle when it is already so cold outside. She elaborated:

So like cold Canada, the cold winter, you shouldn't eat too much ice cream, you shouldn't drink too much Coke, no Coke from the refrigerator. And then also, the ice water is avoided. You shouldn't take too much of the cold thing.

Because the environment itself is cold and then that's going to affect the body and it's about balance?

Right. That's an idea, the human body [responds] to the whole environment (LAW Interview 03/25/03).

Following this line of inquiry, I told Dr. Lau that one of the woman I interviewed who lived with GD, told me that she could not eat watermelon during pregnancy because it was too cold. Dr. Lau responded:

Yes, watermelon. But, you know, that's a very, very, very old idea for the Chinese. In Asian time...the Chinese medicine ask the people to make some certain food very restrict. You know, you just cannot take this part. But today, I don't think that's so important (LAW Interview 03/25/03).

Medications, including insulin, were only used as a last resort to manage GD and Dr. Lau said, "...usually, we don't recommend the pregnant women take too many medications, you know, because of the baby" (LAW Interview 03/25/03). Even though the use of medications is frowned upon by TCM, Dr. Lau commented that in China, the bigger hospitals in urban centres where women would go for treatment of GD, employed both systems of medicine in conjunction:

And usually in China, the big hospitals, they have both systems, Chinese medicine and Western medicine. And when we treat a patient, we always try to use, you know, good part of them, combine them together. We gave them intravenous, the West medicine, and then we use the herbs together.

So you take the best aspects of both Traditional Chinese Medicine and Western Medicine and integrate them together to give comprehensive care to your patients?

Yes (LAW Interview 03/25/03).

From the perspective of TCM, the best way to treat GD was to use herbs or foods based on the diagnosis of symptoms as well as a consideration of individual constitution and the impact of the environment. Yin or Yang foods and herbs would be prescribed depending on the symptoms presented by the woman as well as environmental factors. This emphasizes how TCM views the body as interconnected both within itself, as well as with outside factors, such as the weather. The desired outcome of this treatment was to restore the balance of Yin and Yang in the body and to alleviate the negative symptoms of diabetes for both the mother and her infant.

## Asian Immigrant Women

The Asian women I interviewed told me about their fears regarding GD, the impact it had on their lives and the problems it caused them, as well as the appropriate means to treat their condition. When I asked them what they feared most about GD, all three said that they felt scared, nervous, and worried when their doctors first told them that they had diabetes. The women all expressed fear that the condition would adversely affect their unborn children and that they and the children would become diabetic either immediately after birth or later on in life. Also, Chen said that she was worried her son would be either hypoglycaemic or hyperglycaemic upon delivery.

In addition, two of the women feared the need to use insulin in the management of GD because it would adversely affect their bodies and their babies' health. Chen, the only woman I interviewed who had to use insulin in the management of her GD said, "I feel nervous...I feel this inside. I think I have so many troubles...I inject the insulin and it can't control my high, my blood sugar so I feel this inside" (LAW Interview 28/04/03). She compared how glucose intolerance during her first pregnancy was treated in Beijing as opposed to how GD was treated in Edmonton during her second pregnancy: "...in China, if you diabetes the doctor didn't suggest you use the medical [referring to insulin]...I think the Chinese didn't like the medical because I think it ruin the body, the insulin" (LAW Interview 28/04/03). Jade also said that when she was diagnosed with GD, she worried that she would have to use insulin, which would affect the baby.

After discussing their babies' health, the next concern each woman addressed was their fear that GD would continue to affect their own health. For example, the translator told me that for Tran "...the most concern that her diabetic doesn't go away after the baby is born" (LAW Interview 02/17/03). Jade said that she was worried that she would develop diabetes at a young age and explained through the translator, "With her, she has an idea that she may get diabetic probably around 50 or 60 years old, but not now" (LAW Interview 11/12/02). According to Jade, diabetes is something that happens to older people, not a woman in her thirties. She also expressed a great deal of stress from not knowing if she and her son were still diabetic. Despite her husband's desire for another baby to keep their newborn son company, Jade said through the translator, "This pregnancy is like scare her...she doesn't want to have another one" (LAW Interview 11/12/02).

In addition to asking the women what they feared most about GD, I asked them to tell me what problems the condition had caused them. In general, the women focused on the everyday challenges that managing GD caused them, including self-surveillance and circumscribing routine activities. Tran explained that it was difficult for her to get to her appointments at the clinic. When her husband was not at home, Tran would have to call her sister-in-law for a ride and she said that she felt bad about having to ask. In addition, Tran discussed problems she had in following the recommended diet for managing her GD and said, through the translator:

Usually for our Oriental, rice is the main food for every meal, but since she got the diabetic, the doctor tells her to reduce the amount of rice. So she has to eat bread or noodles, whatever, [because] they don't have much glucose in there...That make her feel that's not very convenient and uncomfortable and affect her eating. Doesn't eat much...it affects her appetite (LAW Interview 02/17/03).

For Chen, it was difficult for her to inject insulin whenever she had to leave the house to run errands. Jade also expressed a great deal of frustration that managing GD caused her on a daily basis:

She has to be really careful with everything, everything have to go into the log book and have to check and counting the times, what, how many hours she have to eat and the amount she is eating. Everything, she have to be really careful...She find out that it really bother her that you had to really check out the time you are eating

and not to over the limit of what you're eating...And make her worry a lot and affect her life. She has to take extra time to be careful with this and you have to watch the food you are eating too...She's says it really bother her, like always have to be really careful that you have to carry that machine [glucose meter] with you all the time. And also you have to watch the time you are eating and the time that you do the test [test blood glucose levels] and it's like, it's really inconvenient...Even though people [are] eating and you say, "Well, my God, it's not time for me to eat yet. I have to sit here and wait"...And if you go out, you have to carry that machine with you and you have to poke [your finger] there and you have to check it and so many things have to worry (LAW Interview 11/12/02).

In addition, Jade talked about the financial burden that managing GD caused her and that she was spending \$100.00 each month on the strips needed to test her blood glucose. The translator went on to explain, "The nurse never told her that you can try to claim your insurance [and] they may pay [for the strips]" (LAW Interview 11/12/02). The largest problem experienced by the three women I spoke with was following the treatment plan given by the Clinic. Problems included paying for the supplies needed, monitoring blood glucose levels, following the diet, and incorporating all these activities not their daily routines. Self-surveillance and the circumscription of behaviours and activities constituted the greatest problem of GD experienced by these women.

Besides asking each woman what she feared most about GD and what problems the condition had caused, I asked them to tell me what they believed was the best treatment for GD and if they had used any other modes of therapy, such as herbs, supplements, massage, or acupuncture. Jade explained that for her, following the recommended diet provided to her by health care staff at the clinic was the best way to treat GD and she was relieved that changing her diet was effective enough so that she did not have to use insulin: "The best treatment she found was with her diet...[clinicians] control her diet good [and] she doesn't need to go insulin, that is the best treatment for her" (LAW Interview 11/12/02). I also asked Jade if she did anything else to help manage her condition and she said she did not use any treatment other than what the clinicians told her to do. Next, I asked her if it was acceptable for a woman to use alternative methods, such as herbs, massage, or acupuncture, in conjunction with treatments offered by the clinic, and she reiterated,

"...just follow the treatment from what the doctor, hospital, dietician tell her what to do is enough" (LAW Interview 11/12/02).

When I asked Tran to tell me what she thought was the best treatment for GD, the translator said, "She happy, very, she feel that the way they instruct her is very helpful" (LAW Interview 02/17/03). I asked if Tran had used any other forms of therapy to manage her condition and she stated, no. Like Tran, Chen explained that she did not use any forms of treatment other than what clinicians told her to do and she said that managing her diet and using insulin therapy was the best treatment for her GD. In summary, all three Asian women stated that the best treatment for GD was to follow exactly what clinicians told them to do, particularly in relation to diet, and none used any other modes of therapy.

# Comparing Conceptualizations of Fear

As with the previous two themes, this section examines the similarities between the women's EMs of GD to those offered by the biomedical or TCM perspectives, as related to 'Fear'. From the biomedical point of view, the greatest fear surrounding GD was the potentially negative health complications for the woman and foetus. This was especially a concern when non-compliance was an issue. The major concern addressed from the perspective of TCM was that harmony would not be restored and the fear was that the mother and infant would continue to experience the symptoms of GD. All three women feared that the health of their babies would be compromised at birth and that both they and their children would develop diabetes later in life, similar to the biomedical perspective. In addition, two of the women I spoke with were concerned over using insulin therapy because it could be harmful to themselves and their babies, which was also an idea expressed by Dr. Lau and present in the TCM literature. While the biomedical approach only utilizes insulin as a last resort in the treatment of GD, its practitioners do not consider insulin to be harmful to either the mother or infant. This was demonstrated in my description of the educational video used in the gestational diabetes class in Chapter 1 of this thesis.

The women's narratives addressing what problems GD had caused them were similar to those expressed by the clinical staff. Both expert groups focused on

the difficulties in managing the condition, including work schedules, financial barriers, and other responsibilities like running errands. However, the women I interviewed did not focus on the symptoms they experienced as the biggest problem to the degree discussed from the TCM perspective, as told to me by Dr. Lau. Instead, their greatest concern seemed to be the permanence of diabetes and the problems vigilance and surveillance in the management of the condition would cause them.

In relation to treatment, the explanations provided by the women living with the condition were similar to that provided by the Biomedical model and the clinical staff I interviewed. All three women stated that the best way for them to treat their diabetes was to explicitly follow the doctor's orders. They all denied using any other modes of therapy to manage their condition. However, I failed to ask these women if they used alternate modes of therapy for other health concerns. Table 5 below provides a summary of the similarities of the women's conceptualizations of GD compared to the explanations offered by Biomedicine and TCM in relation to the theme of 'fear'.

Table 5: Comparing Conceptualizations of Fear

Questions:	Jade	Chen	Tran
What is the greatest fear?	BM/TCM	BM/TCM	BM/TCM
What problems has it caused?	BM	BM	BM
What is the best treatment and outcome?	BM	BM	ВМ

Based on what the Asian women told me, their conceptualizations of GD as related to the theme of fear were very similar to the perspective of Biomedicine. The most obvious expression of this was when the women told me what type of treatment they believed they should have received. All of them explained that a woman should follow the treatment plan provided by the health care workers at the clinic. However, it was difficult to elicit why they believed this was the best treatment in managing their condition. Each time I tried to dig deeper into their understandings of the treatment regime, they would reiterate that a woman should

just do what the doctor told her to do. As was the case when the women talked about the 'problem' and 'process' of GD, their EMs related to 'fear' were largely based on what they had learned at the Clinic.

The previous three chapters outlined the conceptualizations of GD among the three stakeholder groups based on the three themes of Problem, Process, and Fear. The next chapter provides a summary of results as demonstrated by the data, examines the similarities and differences expressed between the expert groups, and discusses the potential reasons for these discrepancies.

The previous three chapters presented the data I collected during this research, organized around the themes of Problem, Process, and Fear. This chapter provides the summary of results, or the conceptualizations of gestational diabetes (GD), as told to me by the three stakeholder groups in Edmonton and demonstrated by the data. This is presented schematically in Table 6. Next, a discussion of the similarities and differences between the explanatory models is discussed. Topics addressed include the philosophical foundations of Biomedicine and Traditional Chinese Medicine (TCM) as well as cultural patterns related to food practices, communication, and compliance. In addition, I offer guidelines for professionals working with culturally diverse populations.

Table 6 presents a summary of the main points in the conceptualizations of GD from the perspective of the three stakeholder groups: biomedical perspective, TCM perspective, and the narratives of the three women I interviewed who lived with the condition.

Table 6: Conceptualizations of Gestational Diabetes by the Three Stakeholder Groups

Key Themes	Biomedicine	TCM	Asian Women
Label/ Description	- Gestational Diabetes - Glucose intolerance - Recognition during pregnancy	- Gestational Diabetes - Symptoms of thirst and frequent urination - Diabetes during pregnancy	- Gestational Diabetes
Etiology/Cause	- Metabolic disorder - Hormonal stress due to growth of the foetus, resulting in an increased demand for insulin	- Meridian (organ) system disorder - Deficiency or Excess of Yin or Yang - Typically, a deficiency of Yin and the body's inability to regain balance during pregnancy	- Older age at conception - Inherited from family - Diet: eating too much meat, sugar, or oily foods and fewer vegetables
Risk Factors	1) Family history of diabetes 2) GD in previous pregnancy 3) Macrosomic infant 4) Overweight/ Gaining too much weight 5) History of stillbirth or miscarriage 6) Multiparity 7) High-risk ethnic group	Primary: 1) Individual Constitution  Secondary: 1) Family history of diabetes 2) High blood pressure or cholesterol	1) Family history of diabetes 2) Poor diet 3) Lack of exercise 4) Age
Timing	- 2 <sup>nd</sup> to 3 <sup>rd</sup> trimesters	- Any time during pregnancy	- When the doctor diagnosed it
Pathophysiology	- Body's ineffective use of insulin causes high blood glucose levels	- Imbalance of Yin and Yang results in the symptoms of diabetes	- Do not know - The presence or absence of symptoms

Degree of Severity	- Very severe	- Very severe	- Very severe
Cessation	- Shortly after delivery	- Shortly after delivery	- Do not know
Fear	- Adverse health outcomes for mother and infant - mismanagement of GD	- Experience of symptoms	- Baby will be sick - Baby and mother will develop diabetes - Fear of using insulin
Problems it caused	- Problems related to compliance	- Experience of symptoms	- Problems following recommended treatment
Treatment	- Diet, exercise, monitor blood glucose levels, and insulin	- Food, herbs, and acupuncture - Insulin as last resort	- Biomedical treatment plan provided by the clinic - Do not want insulin therapy
Desired Outcome	- No health complications for mother and infant - GD ceases in mother after delivery	- Mother and infant do not experience symptoms of GD - Restore balance of Yin and Yang - GD ceases after delivery	- Baby is healthy - GD goes away - Baby and mother do not develop diabetes

### Similarities between the Three Stakeholder Groups

The explanatory models (EMs) of GD were the same among all groups in three areas: the term they used to label the condition, its degree of severity, and the desired results of treatment. Every participant labelled the condition as 'gestational diabetes'. However, while the Asian women I interviewed only gave me a name for the condition, the biomedical and TCM models provided a more detailed description of the term, 'gestational diabetes'. The biomedical model also defined the condition as 'glucose intolerance' and described it as a metabolic disorder with onset occurring upon first recognition during the second or third trimester of pregnancy. In contrast, the TCM model defined GD as 'gestational diabetes' and described it as the imbalance of Yin, resulting in the presence of symptoms. The condition could occur

at any time during pregnancy and was highly dependant on a woman's individual constitution and interconnected with outside factors, such as the environment.

Even though the Asian women that I interviewed labelled their condition as GD, it does not mean that they understood it in the same ways as the biomedical and TCM perspectives. First, all three women had participated in a gestational diabetes class at a diabetes outpatient clinic before our interviews. The term GD could have been integrated into their EMs at this point. Second, there was no competing terminology used by TCM for the women to have utilized instead. Third, the translation process during our interviews may have affected the label two of the women used for their condition. My supervisor mentioned to me that she found it interesting that none of the women called their condition, 'sugar disease' or something similar and that instead they used the technical term offered by Biomedicine and TCM. Upon reflecting on the fact that my translator was going to school in Edmonton to become a nurse, I realized that the women I interviewed might have called their condition something else and the translator substituted her own technical knowledge perhaps assuming that that was what I wanted to hear. These problematic issues make it impossible to generalize that just because the three stakeholder groups used the same term to the label the condition, they understood its meaning in the same ways.

However, it was apparent that the conceptualizations of GD among the stakeholder groups were extremely similar in relation to how severe they considered the condition to be. Every participant I interviewed stated that GD was a very serious condition affecting pregnancy. In addition, all three groups provided similar explanations regarding the desired outcomes of treatment. Every group hoped that the mother and infant would be healthy upon delivery, that they would not develop diabetes later in life, and that GD would go away. There was slight variance in the responses, especially in regards to the TCM model that focused the expectation of treatment primarily on the relief of symptoms, but the underlying hope and expectation that the mother and baby would be healthy and that GD would cease were the same across the three expert groups. The next two sections analyze the similarities between the women's conceptualizations of GD with those of Biomedicine and then TCM.

# Similarities in Conceptualizations of GD by Asian Women and Biomedicine

The EMs of GD presented to me by the women living with the condition were very similar to those provided by clinical staff and the biomedical literature in several areas: when the condition started, the problems it caused, and appropriate treatment. The women stated that their condition started when their doctors first diagnosed them as gestational diabetics but they did not elaborate on why GD started when it did. In addition, both groups had similar conceptualizations in regards to the problems faced by this group of women dealing with the condition and the appropriate means of treatment. In relation to the problems encountered, topics included inflexible work schedules, school obligations, and financial barriers to buying the needed supplies.

Even though their responses to the question of what problems GD caused were similar, it is important to note that the clinician's framed their responses around compliance while the women framed theirs around the real life difficulties they encountered trying to follow the recommended treatment plan of the Clinic. In fact, when I asked clinical staff what was the biggest problem GD caused, they all responded that the major problem was the few cases where women did not comply with the Clinic's disease management. However, GD does not cause non-compliance. For clinical staff, the problem was non-compliance leading to less than optimal blood glucose levels and potentially resulting in health complications.

The Asian women I interviewed framed their concerns around how difficult it was for them to follow the recommended treatment plan provided by clinicians. They stated how inconvenient it was for them to test their blood glucose four times a day, to eat at specific times, to change their diet, and to remember their meters when they left the house. Many of their concerns revolved around when they had to leave their houses to run errands or go to work. The women's responses were centred on the everyday problems that following the recommended treatment of GD caused them, specific to self surveillance and circumscribing regular activities, like going out for lunch with friends.

Even though the women cited everyday issues related to following the treatment plan provided by the Clinic, their conceptualizations of GD regarding

appropriate treatment was similar to clinical staff. Biomedicine recommends an approach that includes modifications to diet and exercise, monitoring blood glucose, and using insulin therapy. All of these techniques are taught at the Clinic during the gestational diabetes class and promoted during follow-up appointments. All three women I interviewed told me that the best treatment for their GD, and for that of any other woman suffering from the condition, was to follow the instructions of the clinical staff. When I asked them if they used any alternate forms of therapy, each said no and reiterated that a woman should follow the orders of her doctor. When I asked if it was alright for a woman to use other means of treatment, such as massage therapy, herbs, teas, or acupuncture, Jade said that a woman should follow the orders of her doctor. Although the women told me that the biomedical treatment regime was the best way to treat their GD, none of them explained why or how the treatment worked.

In addition, even though the women's conceptualizations surrounding the treatment of GD were similar to what the biomedical model promoted, their fear of insulin therapy was far more pronounced than that expressed by clinical staff. Biomedicine relies on diet, exercise, and monitoring blood glucose levels as the primary tactic in managing GD. Insulin therapy is only used as a last resort when the other three methods are insufficient in controlling blood sugar. However, when it is required, health care providers do not consider insulin to adversely affect the health of the mother and infant. In contrast, the women I spoke with explained that insulin therapy should be avoided because it could negatively impact health.

### Similarities in Conceptualizations of GD by Asian Women and TCM

While the women I interviewed employed some aspects of the Biomedical model in their conceptualizations of GD, they also incorporated several features of the TCM model. One of the most notable areas of similarity centred on the discomfort of using insulin therapy, as I discussed in the previous section. Two of the Asian women, as well as Dr. Lau, explained to me that a pregnant woman should not use insulin because it would affect the baby. I regret not questioning the women of these two expert groups further on how insulin would affect the foetus but the manner in which they told me that insulin was not appropriate demonstrated that

this was implicit, taken-for-granted knowledge. It reminded me of how I would respond if someone asked me why I would not smoke while pregnant, "Because of the baby"!

In addition to the understanding among Asian women and TCM that insulin therapy should be avoided for pregnant women, the members of both groups demonstrated a similar explanation for how GD worked in the body. It is important to note that their explanations are not exactly the same; Dr. Lau's explanation was more explicit while the Asian women's explanations were more vague. However, their conceptualizations of the physiopathology of GD were far closer to each other in meaning than they are to the biomedical perspective. While Biomedicine conceptualizes the process of GD as the body's ineffective use of insulin, TCM and the women I interviewed described the workings of GD in relation to the symptoms it produced. One woman I spoke with explained that GD 'worked' by making her thirsty and tired while another woman explained that she had no idea how GD worked because she did not experience any symptoms. The lack of symptoms left her without a way to explain the processes of GD. The third woman told me that she had no explanation for how GD worked in her body, while she motioned vaguely towards her stomach.

Besides focusing on the symptoms, or lack thereof, to explain how GD worked in the body, Jade mentioned the concept of balance. This is very interesting because when I asked the women explicitly if they could talk to me about the concepts of Yin and Yang in relation to their condition, none of them could. They just shrugged their shoulders or looked at me blankly and explained that they did not know anything about Yin and Yang in relation to their GD. However, Jade began speaking implicitly about balance and pregnancy later into our conversation:

[T]he pregnant woman is different. You have to be careful with your diet [and] you don't eat certain kinds of foods. They say it make your body, how is it said? Make your body, your circulation, everything is very cold. It can easily affect the pregnancy, like you be miscarriaged (LAW Interview 11/12/02).

Even though Jade did not talk about balance using the terms of Yin and Yang, the notion of balance was part of her EM for understanding pregnancy and what a woman should do during this time.

In addition, Chen discussed notions of harmony and the influence of outside factors on having a healthy pregnancy. She explained to me that a pregnant woman should not watch too much television or sit in front of the computer screen for long amounts of time because the rays would be harmful to the baby. Also, she explained how her mother told her to eat lots of walnuts to help the foetus' brain grow and eat carrots to ensure that the baby will have a good skin complexion. While neither woman explicitly talked about how balance related to their condition of GD, they made other comments that highlighted how this notion underlies some of their conceptualizations regarding pregnancy. I realized when thinking about the women's vague yet implicit understanding that the body worked in certain ways that I had no specific explanation for the common Western statement that 'an apple a day keeps the doctor away'. This folk epistemology has been incorporated into Biomedicine and it is popular saying among professionals and lay people. However, I cannot explain explicitly how eating an apple everyday works in the body to prevent illness and thus a visit to the doctor.

Dr. Lau's response to my question of how GD worked centred on the notion of disharmony of the meridian system and although it was far more specific, it was similar to the Asian women's focus on balance and symptoms. According to TCM, GD resulted from a deficiency of Yin resulting in the weakening of the kidney, spleen, and stomach function. Because the body is interconnected along the lines of the meridian system, disharmony in one area of the body, such as the kidneys, will be displayed in other areas, offer externally. Typically, this results in presence of symptoms. The diagnosis of symptoms of GD is the best means to determine the most appropriate treatment. Even though the EMs of the women who lived with the condition and the TCM doctor were not exactly the same, the underlying emphasis on symptoms and balance to conceptualize how GD worked in the body was similar.

# Differences between all Three Expert Groups' Conceptualizations of GD

To this point, I have analyzed the similarities between the stakeholder groups in their conceptualizations of GD. This section analyzes the areas in which the

Asian women's conceptualizations of the condition differed with that offered by Biomedicine and TCM explanations.

Of the three Asian women I interviewed, one had no explanation for the cause of her condition but later explained that her doctor in Edmonton told her it was her unhealthy diet and lack of exercise that resulted in diabetes during this pregnancy. Jade explained that she had inherited her condition from her mother, who had recently been diagnosed with Type II diabetes. This explanation falls in line with Biomedicine, which lists a family history of diabetes as a potential risk factor for the development of GD. In contrast, Chen's explanation that the cause of her GD was eating too much oily food and meat was more reflective of the TCM model. It is in relation to the cause of GD that the greatest difference between the explanatory models of Asian women in comparison to Biomedicine and TCM is demonstrated.

Biomedicine and TCM both place an emphasis on balance in the body when it comes to GD, but to different degrees. In Biomedicine, the cause of GD is explained as extra hormonal demands due to pregnancy that the body does not adjust to. In other words, the body is out of balance because blood glucose levels are fluctuating past normal levels. To a greater degree, TCM focuses on disharmony in explaining the cause, diagnosis, and treatment of GD. The condition results from an imbalance of Yin and Yang where the body cannot readjust to the new state of pregnancy. Disharmony in the body is manifested in physical symptoms. Treatment focuses on re-establishing balance. However, the women I spoke with who lived with the condition did not concentrate specifically on the idea of balance. They considered the cause of GD to be something inherent to their situation, such as age and heredity, or as a result of external factors, such as eating too much sugar or not exercising enough.

The women's conceptualizations regarding when GD would end demonstrates how neither model had been incorporated into their understandings of when they would be cured. While both Biomedicine and TCM asserted that, in most cases, GD would cease in the mother shortly after delivery, none of the women I interviewed could tell me if they still had GD or when they would be cured of the condition. This uncertainty caused the women a great deal of fear and stress.

### Discussion

As was mentioned in Chapter 2 of this thesis, EMs cannot be removed from the social habitus, including the cultural, historical, or political contents, of the participants who employ them. The differences demonstrated between the three stakeholder groups in their conceptualizations of GD are based in culturally constructed patterns of behaviour and knowledge. For example, the medial canons of Biomedicine and TCM are culturally and historically constructed and as such often reflect and perpetuate the dominant values of each society in which they are grounded.

# Comparing The Cultural Constructs of Two Medical Traditions

From the perspective of Biomedicine, the EM of GD focuses on the physiological conception of the condition as a metabolic malfunctioning where non-compliance to the specific treatment regime results in dire consequences for the health of mother and infant. Based on the patient education model, the biomedical approach to the treatment of GD is generalized for all women, including their bodies and circumstances. From the perspective of TCM, the conceptualization of GD centres on the manifestation of symptoms as an indicator of the physiology, the imbalance of Yin and Yang, its affect on the meridian system, and the proper means of treatment. With the focus on symptoms, the TCM approach to treatment is tailored to individual women. The differences demonstrated between the two medical models in their understandings of GD can be explained, in part, on the basis of their philosophical foundations. The following section compares the two medical traditions based on their conceptualizations of the body and how these maintain the status quo of the dominant values of each society.

The conceptualization of the body, from the perspective of Biomedicine, is based on the Cartesian model of mind/body dualism (Foucault 1973). Historically, this framework developed out of the Enlightenment during the struggle to separate knowledge from religion. This dyadic model has become entrenched in Western thought and includes the division between objective (nature) and subjective (experience), interior and exterior, nature and society, natural and supernatural, profane and sacred, nature and culture, as well as individual and society.

Biomedicine's conceptualization of the body and the objective to find and cure the physical mechanism of disease is based on the Western values of individualism, autonomy, freedom, and rationality (Gordon 1988).

Based on this framework of reductionism, the geography of the body was conceptualized as a machine where the individual parts became more important and knowable than the whole<sup>20</sup>. Each part was viewed as independent or autonomous from another and only by knowing all the parts could one reconstruction of the body (Foucault 1973). In Biomedicine, the focus of study became the 'disease', framed within the germ theory, rather than 'illness', the social experience of symptoms and the knowledge about them (Kleinman 1980 and Young 1982). The objective was to discover the pathogen or sign causing the disease and to treat and cure that individual agent (Gordon 1988). Therefore, disease becomes validated through the manifestation of observable physical malfunctions rather than the experience or illness narrative of the individual.

In contrast to Biomedicine, TCM conceptualizes the body as an integrated whole that is interconnected with every aspect of life, including the mind, spirit, nature, and society. Historically, this framework developed out of the explanation for the creation of the universe, which was conceived in terms of reproduction and the union of opposites, labelled as Yin and Yang (Mahidhassan 1988). The principle of Yin and Yang extends beyond an explanatory model for the origins of the universe and has been "…incorporated into the applied sciences, such as medicine and geography" (Tang 1995: 272). Typically, all things in the universe can be classified as either possessing Yin or Yang qualities, including foods, herbs, bodily functions, diseases, and stages of life (Tang 1995). The interplay between the forces of yin and yang create Qi (Mahdihassan 1989). Qi is defined as "…the vital energy that is behind all physiological processes" (Ehling 2001: 71).

The concept of Qi, as the vital life force circulating through an individual, and the importance of balance in maintaining the inhibited circulation of Qi has led practitioners of TCM to formulate a geography of the body different from that

<sup>&</sup>lt;sup>20</sup> Here, I use the term 'reductionism' to refer to one way of looking at the body that is employed by the biomedical model where the construction of the body and any malfunctions, such as illness, are conceptualized in biological terms. The term does not refer to oversimplification.

developed in Biomedicine. The geography of the body is conceptualized as an integrated whole based on a meridian system. For instance, Ehling states:

The ancient masters traced pathways through which qi passes and located points along them at which the qi communicates with the surface of the skin. These are the points that are used during acupuncture therapy. All organs are interconnected with each other by way of this meridian network system" (2001: 72).

Because the body is connected via meridian lines, it is viewed as an interconnected system where "...disease in one organ may affect another" (Ehling 2001: 72). Points along the meridian lines interact with the surface of the skin and practitioners use these external signs to diagnosis and treat disease. TCM maintains that the basic principle working in the body is balance. The body is irreducible to separate parts autonomous from one and other and, therefore, harmony between the systems of the body must be achieved and maintained to promote or regain health.

The emphasis in diagnosing and treating a condition is on the manifested symptoms because the meridian system communicates with the surface of the skin, which reveals imbalances between Yin and Yang and the inhibited flow of Qi. Avery and Avery state:

In the process of understanding disease through the concepts of Yin and Yang, [practitioners] must learn to recognize the external symptoms of disequilibrim of energy in a particular organ or organs and the overall conditions of the sick person. Oriental doctors rely on the patient's physiognomy, the color of the complexion, the appearance of the eyes, tongue, hands and feet. Also considered are the sensitivity to pain on certain acupuncture points of the body, especially the extremities, the backbone and the abdomen (1981: 149).

Illness is conceptualized as the disharmony of balance, which manifests itself in external signs and symptoms.

Based on the geography of the body as an integrated whole, health and disease is influenced by and interconnected with the physical environment, such as biology and nature, as well as the social environment, including abiding by accepted norms and personal obligations. For example:

Oriental medical theory relies on correspondence thinking: the functioning of our body interrelates closely to the natural laws of the world around us. Because the human body is a microcosmic

manifestation of the macrocosm around us, we are influenced by the weather, the food we consume, everything we see, the sounds we hear, the emotions we feel, and all the things that touch us, including other humans. When we are at balance with all these influences and, most important, within ourselves, we are healthy (Ehling 2001: 71).

The TCM conceptualization of the body as interdependent mirrors the dominant value placed on family and social obligations above the individual (Leininger 1991). Social responsibility and duty emphasizes the individual's integration and role as paramount to the family unit and larger society.

The previous section examined the differences between the medical models of Biomedicine and TCM in their understandings of GD based on differing philosophical, cultural, and historical foundations. As demonstrated by my presentation of the data in Chapters 3 to 5, the Asian women's EMs of GD incorporated several aspects of both models.

During the process of developing their EMs of GD, the women were engaged in a process of transculturation by synthesizing aspects of the biomedical and TCM conceptualizations of the condition. Pratt explains that transculturation is the "...phenomenon of the contact zones" (1993: 7). The contact zone of the Clinic is the spatial and temporal interaction of different cultural groups that had previous been separated but are now in contact due to the condition of GD. In the context of the Clinic, transculturation relates to the marginalized group of Asian women who select and integrate aspects of the dominant medical models transmitted to them. They do not have direct control over the information they are given, particularly in relation to the patient-education model employed by the Clinic, but they do determine what types of information they accept, tolerate, transform, and utilize, which was demonstrated by the data.

The next sections discuss the cultural norms of diet, communication, and compliance in the conceptualizations of GD among the three expert groups. In particular, the issues of diet, communication, and compliance were intertwined in the biomedical clinician's narratives, where compliance of women with GD to their recommended treatment regime was determined by what one clinician called, "Asian women's unchanging and simple diet", and the clinician's perceived successful negotiation of language barriers.

#### Culture and Diet

Both Biomedicine and TCM place a huge emphasis on the management of GD through the use of foods. From the perspective of Biomedicine, the proper selection of foods and maintaining a grazing pattern of eating meals and snacks helped the body maintain close to normal blood glucose levels. In contrast, TCM conceptualized diet as a means to restore balance to the body based on the metabolic characteristics of foods and herbs. Additionally, foods and herbs were used to alleviate the symptoms of GD.

One of the biomedical staff I spoke with talked in detail about her perceptions of Asian women's diets:

Their breakfast, lunch, and supper is always the same and snack is basically the same and breakfast can vary a little bit but, they're very easy to teach, very easy actually to teach...Lunch and supper is always the same thing. It's always rice, at lunchtime it's always rice and some meat and some vegetables. Many of them will have a piece of fruit after their meals, orange is quite popular, something in there. And usually they drink tea and suppertime would be the rice or the noodle and then again the meat, the vegetables, and in some days the rice or the noodle and they always have the soup at suppertime but their soup is like clear broth soup. And that's their beverage at the same time. And quite often they will have a piece of fruit with suppertime. And in between their meals again, it would be the fruit and, occasionally, maybe the crackers. In general, they are not much on our sweeter kinds of cookie. So, it's more like plain crackers and breakfast, typical breakfast for them would be some toast, often an egg or ham, ham is fairly popular with them...And, some of them drink milk and some of them don't drink milk. So, and often it's not a lactose intolerance, they just don't do it. So, I do explain why it is important and they're very, they're very good at, if you suggest something, to do it (LAW Interview 04/03/03).

I asked this staff member if she had investigated other types of foods rich in calcium that may have been preferred by Asians as an alternative to milk and she stated that she had not explored this option. Later during our interview, I asked her what kinds of questions Asian women asked in relation to GD and how they differed from those asked by mainstream Canadian women and she said:

We don't get the questions that often. Probably less often, very seldom...But, probably their concern, I think it's a culture thing. It was their culture...you know, because they have a lot of myth, I think,

different ideas, Asian people. And certain foods and something like this, you know? I could not tell you any like this, but I know they have certain foods they won't eat. But usually does not interfere with their meal plan because it's only certain foods, so if they cannot eat that food, that's okay (LAW Interview 04/03/03).

I asked another clinician if she was familiar with the concepts of Yin and Yang and if they ever came up during appointments with Asian women:

Well that comes up and again, I think not so much with what I do, I hear about it. But it's that hot/cold food, it's the hot, well yes, the balancing of the nature, natural forces or the balancing act that, you know, very, I wouldn't call them orthodox. What would the word be? Traditional Chinese people prefer, traditional Chinese people they're influenced by that. Especially if they live in a home where there are extended families, especially elders. Not elders but their parents or grandparents or if she's female, it's usually his family. So there's those kind of influences and traditionally, yes they do, are aware and do take care.

Right and follow that. So you don't find it mentioned as much in your aspect of treatment and management as far as I guess maybe processes in the body and being out of balance?

Not really. But then, it's not, I don't, they don't tell me.

Okay. So they're not mentioning it. But you've heard about it a little bit maybe with the diet?

Well, the diet and the food tends to be, and it always comes to mind, hot/cold, that always is the big...and not just temperature hot/cold but like warmth and cool foods (LAW Interview 04/03/03).

Based on the clinician's narratives, they had some idea of the notion of Yin and Yang and its relation to food and diet and they considered the Asian diet to be simple, homogenous, and unchanging, which they believed assisted them in providing education about diet to this group of women.

It is interesting to compare the notions clinicians had regarding diet and those of the women I interviewed who had lived with the condition. The women told me that they strictly followed the recommended treatment, including diet, offered by clinical staff and stated that the concepts of Yin and Yang were not important to them. Although the women I interviewed did not explicitly mention the concepts of balance and harmony or Yin and Yang, these notions were made

implicitly during our conversations and often related to food or diet, just as they were when we discussed the state of pregnancy and what a woman should do during this time.

For example, when discussing the cause of her GD, Chen said that she ate too much oily food upon arriving in Edmonton. Similarly, Jade told me that a woman should not eat oily foods in order to ensure a healthy pregnancy. I asked Chen what a woman should eat in order to help ensure a healthy pregnancy and she said:

Eat more fruits and vegetables, eat more...I can't...just a moment (she yells upstairs to her husband to find the correct English word). Let me eat more nuts, it's walnuts...It's very good for the baby's brain (she laughs). In China they think the first months of the brain is the growth so you eat more.

More walnuts to help the brain develop in the first few months?

Yes.

And are there any other types of foods that you should be eating?

Eat more apples...[my mother] tells me apple is good for the skin...and more carrots for the bones (LAW Interview 04/28/03).

Continuing along these lines, I asked Chen if there were any ideas of hot or cold foods that go along with pregnancy, and she said, "No". Then she continued:

It's just eat and when you birth the baby the cold is very important for you...especially for the woman...Yes, the mother. If you, so in China, we have one side, one month don't go outside unless (cannot understand one word) and you don't go bath. Yes. And you don't cut your hair because if you do this then you feel the back pain.

You'll get back pain and it means that your body is getting too cold?

Yes...The difference is in China, when you birth the baby you don't drink ice water. In [Edmonton] everyday! (She laughs).

[Hospital staff] gave you ice water?

Yes!

So you probably didn't drink it then?

I think it's okay (LAW Interview 04/28/03).

Although she did not explicitly relate the notion of harmony to diet, Chen did explain that eating oily foods caused her to develop GD and she also commented on what types of foods a woman should eat to ensure a healthy baby. In addition, she discussed the notions of Yin and Yang regarding the postpartum period and laughed hysterically at the fact that staff had given her ice water to drink. However, she did accept and drink the cold water indicating that her EM surrounding what a woman should do postpartum had begun undergoing change based on her experience in an Edmonton hospital.

Jade also discussed the postpartum period and what a woman must do to stay healthy during pregnancy and everyday life. In regards to the postpartum period, Jade explained through the translator that, "...her body's a bit weak right now because of, she is breastfeeding right now and that her body is pretty weak right now she may catch a cold easily" (LAW Interview 11/12/02). She continued discussing breastfeeding and said:

And also she afraid that the baby may get ill and she, it's also from food and sometime, like she for herself she say she got ill if she eats spice. It's all kind of spice. That's why she afraid she may pass those allergies to the baby, the baby may get those allergies and also, she may pass the cold or fever... (LAW Interview 11/12/02).

Later on during our discussion, I asked Jade if pregnant women in China received any special status and she discussed at length issues of balance and compared treatment in Hong Kong to that in Edmonton, through the translator:

So the difference in there is like with the pregnancy woman is like different, is like, you have to be careful with your diet, you don't eat certain kinds of foods, like, they say it's you make your body is, how is it said? Make your body, your circulation, everything is very cold. It can easily affect the pregnancy, like you be miscarriaged like some certain kind of food, like for example, a lot of them say watermelon you can't not eat before certain month like three months, two months of pregnancy. But in here, with the doctor here they won't tell you like you can eat whatever you want, whatever you want. But over there, they would tell you be careful of the food and also not to carry anything's too heavy. That you may go to miscarriage and also it's a big difference, it's like after the baby is born, they won't discharge you for a day, they won't allow you to get off the bed. They won't allow you to have a bath or anything or shower, not touching the water. And if you breast feeding, they will bring the

baby to you. It is for a normal delivery but if a C-section, they may keep you longer and talk to the doctor but in here she says it's like with a normal delivery they will send you home 15, 24 hours. If they think that you okay, you can stand up and then they ask you to get up and go and have a shower or bath. In Hong Kong, they really treat you special, different than other people. Like you have to stay in bed for the whole day, not allowed to go have a bath or shower, not touching the water, like those kind of things. It's different...And she said that it is totally different and the way she talk she's just more suggests that what they did in Hong Kong is a new mother have to be staying for that day to maintain the health.

Yes, to get a little rest after...

And after touching the water, she said like for her right now she's follow a lot, she follow the Canadian style, Canadian style here, she still have a shower in the day or two. But, like, back in Hong Kong, lots of people don't allow you have a shower, touching the water for the whole month.

Right, right. Oh, for the whole month?

Yes, and right now like right [now], Hong Kong it start to change. A lot of them still have a bath or shower but not [for] a day.

Right, not a couple hours after the birth (translator and I laugh).

Yes, not like here...can get up and go have a bath and wash it, no they don't (LAW Interview 11/12/03).

Like Chen, it appears that Jade's explanatory model surrounding what is acceptable for a woman to do after birth is changing.

# Cultural Patterning of Communication/Language

When I began this project, I was interested in how language barriers were negotiated between the women and clinicians during their appointments. I was particularly sensitive to this issue because I required the services of a translator when interviewing Asian women about their condition. I wondered how much more difficult it was to communicate complex health and treatment issues to someone who spoke another language. Here, I discuss what the women and clinical staff told me during our interviews in relation to language barriers.

I asked the Asian women I interviewed what they did when they went to an appointment and the clinicians did not speak their language. I asked Tran if any of the medical staff at the Prairie Hospital spoke Vietnamese and she responded that Phat did, who was one of the translators hired by the hospital<sup>21</sup>. Next, I asked Tran if she ever went to an appointment when Phat was not there and she said, through the translator:

It seems like every time she visit there that Phat is there except at the labour. Phat was not there. Even though Phat is not there...[Phat] still call from home to translate through the phone. Even though he can't show up and that either (LAW Interview 02/17/03).

Tran explained that the one time the translator could not come for interpretation was during her labour but that he called her throughout the delivery to translate for her over the phone.

Jade had a similar experience to Tran and explained during our interview that none of the staff at the clinic spoke her language but that Phat, the translator, was always in the building and could be paged. Based on this comment, I had assumed that the interpreter accompanied Jade to all of her appointments at the clinic but discovered that this was not the case when I asked her if she understood everything the clinicians told her:

Basically, she understands like for the basic questions...like the interpreter not coming so she just there by herself and she says she understands all the basic questions and like, if she want to ask furthermore about health or anything, she can't because she doesn't know how to ask them. She doesn't understand all the details the doctor explain to her. She can only understand the basics (LAW Interview 11/12/02).

There were times that an interpreter was not available to assist Jade during her appointments and she could not ask any questions regarding her health, the treatment, or her baby's health.

During my interviews with Jade and Tran, I used an interpreter. However, Chen was comfortable conducting our meeting in English without the assistance of an interpreter but I was curious if anyone at the Clinic spoke her first language and she said:

<sup>&</sup>lt;sup>21</sup> A pseudonym has been used in place of the translator's name to protect his identity.

In the last [appointment] one doctor is speak Mandarin, a little. He is Cantonese.

And did you get to see him and talk to him about your diabetes in your own language?

Yes.

Before that, before you met the Cantonese doctor, was it difficult to communicate with your doctors?

A little.

A little bit? Okay. You seem fairly comfortable with English?

Yes.

For everyday, but then when you start talking medical conditions there's probably some words that you don't normally use?

Yes (she laughs). I think the Mandarin is better for me because I can understand what you say but I can't describe my mean [feelings]. It's difficult for me (LAW Interview 04/28/03).

Although Chen was comfortable speaking with me in English during our interview, most of her responses to my questions were either 'yes' or 'no' and she did not elaborate on her answers. It seems apparent, based on her response to the last question that she would have preferred to communicate with clinicians in her first language so that she could express how she was feeling.

In addition to asking the women what they did when language was an issue for them during their appointments at the Clinic, I asked the staff how they dealt with language barriers. One of the clinicians explained to me that communication issues in the clinic could be handled in various ways and included the use of family members to interpret, translators provided by the Prairie Hospital, interpreted information sheets, and visual demonstrations, such as pictures or charades. I found it interesting that all three clinicians I spoke with preferred to handle language issues in completely different ways demonstrating that there was no official protocol.

For example, one of the clinical staff said that she used a family member, such as a husband, to translate information and only called in a professional translator if a family member or friend were unable to attend the appointments. She

commented the receptionist tried to book the same two or three interpreters for appointments in order to maintain consistency. She stated, "...they can interpret [the information] but it's kind of *how* they interpret it and if you have the same people you get to know them and they get to know you and certainly that trust is there" (LAW Interview 04/08/03). This staff member explained that by using the same translators, these professionals were able to learn more information about GD and its management to convey to the patient. She elaborated that the translator's comfort with the educational material helped improve the quality of communicating with the patient. For example, in regards to using the blood glucose meter, she said, "I find [these interpreters] can just kind of take the patient aside and go through how to use the machine and all that stuff themselves" (LAW Interview 04/08/03).

I asked her what she did when a family member or an interpreter was unavailable for her appointments with Asian women who did not speak English. She explained that often patients requiring a translator had been to the clinic several times before, for follow-up appointments, and therefore, they were already comfortable and familiar with the routine. She related an experience she had with a patient the previous week and stated, "...she wasn't a new appointment. She'd been coming a few times and so she was fine, she could just show us everything, what she was doing" (LAW Interview 04/08/03). Furthermore, she told me the physician working that particular day spoke Chinese.<sup>22</sup>

She continued discussing language barriers and explained that she relied on pamphlets interpreted into Chinese characters to give to patients for educational purposes. As a last resort in negotiating language barriers, this clinical staff member said that she used visual demonstrations to convey information. She said that it must be more difficult for the dieticians to deal with language barriers because they must discuss diet, "...whereas if I'm demonstrating how to use the meter, I can show [the patient] how to use it and we just go over it, you know, and they just pick it up. It's not like I have to delve into the mechanics of the machine or something" (LAW Interview 04/08/03). According to this health care professional, language barriers could be dealt with and in her opinion they did not pose a significant barrier in educating Asian women on GD management.

<sup>&</sup>lt;sup>22</sup> Margaret did not mention which language, Mandarin or Cantonese, the physician spoke.

In contrast another staff member of the Clinic that I interviewed explained that she preferred to use an interpreter provided by Multicultural Services at the hospital rather than relying on a family member to translate in cases where language was an issue. For example, when using an interpreter, she stated:

[T]he message that I give or the directions I give go maybe more directly [to the patient] then when someone brings a family member along. I'm not sure whether the message...I don't think it's like directly translated when I say something to the patient that the patient hears exactly the words that I say. I guess it can't because the language is different, but the message, I'm not sure if they get it (LAW Interview 04/03/03).

Even though she preferred to use a translator to family members when language barriers were present, she stated, "...when you work with an interpreter, I'm never exactly sure what the interpreter is saying" (LAW Interview 04/03/03).

While one clinician preferred to use family members and another preferred the use of professional translators, the third staff member I interviewed said that she preferred, whenever possible, to speak directly to the patient in English. For example, she stated:

They don't speak English because they are afraid to speak it. And then I can tell when I'm talking with them and talking with the interpreter and all this, that I will say something and they understand what I said. So, I point to them and I say, "You can speak English and you can hear English. You can understand English". So there's a big grin. So, when I realize that, I really try again to communicate with them in English...once you break that barrier, it's amazing. They'll speak to you! (LAW Interview 04/03/03)

She explained that she felt more comfortable knowing exactly what was said to the patient rather than assuming the translator had interpreted the information correctly. She also addressed issues of gender when it came to using a translator:

[T]his hospital has a Chinese interpreter so now we use him. He's a fellow. I always feel for [women] that I like to have a woman talking to a woman [rather] than a man talking to a woman. This is, I don't know?

Because it is dealing with pregnancy?

Yes, yes. And I feel that, I don't know, I just like it better. Just having a woman talking to a woman and maybe it depends on the

man too but we all have our own feeling about, you know, how people related to another person (LAW Interview 04/03/03).

In addition, this clinical staff member stated that she was confident in her ability to educate women who did not speak English through the use of posters and a few informational pamphlets, which had been translated into Chinese characters.

Therefore, she did not consider language barriers as an obstruction in her ability to convey information and instruct Asian women in the management of GD.

One potential factor contributing to the poor negotiation of explanatory models between these two groups is the existence of language barriers. Multicultural Services at the Prairie Hospital provides interpretive services to help bridge language gaps between health care providers and patients. However, the Clinical Director estimated that translators were available in only approximately 80% of cases where they are required for appointments at the Clinic. The clinical staff listed techniques they used to overcome language barriers when an interpreter was unavailable, such as the use of family members, posters, and translated information pamphlets.

What implications do the differing of opinions in relation to how best deal with language barriers at the Clinic affect Asian women? It appears that it is the clinical staff that decides what to do when language is an issue. None of the clinical staff I spoke with said that they would first find out what their patient preferred and then take appropriate action based on this need. When a health care practitioner decides to usurp the role of the translator and conduct the appointment in English, a patient may feel she has no option except to continue her consultation in the language of the staff member's choice. Not allowing a patient to use a translator when available takes away her voice during the appointment. Also, it is the preference of clinicians whether or not to use family members as translators. Again, this is problematic. Some women may want a family member to act as a translator in order to help retain specific information later, when she is at home and trying to implement the treatment program for GD. On the other hand, some women may value privacy or do not want to burden family members with their health issues, in which case using a husband or child as a translator would be extremely inappropriate.

# **Cultural Patterning of Compliance**

While conducting this research, I came upon something interesting that I did not expect: Asian women were highly compliant with their recommended treatment plan even though the data I collected demonstrated that the two expert group's explanatory models of GD differed significantly in several important areas. I must admit that I expected the Asian women I interviewed to have told me that they did not agree with the treatment regime promoted by the Clinic and for the clinical staff to have said that this ethnic group of women were difficult to treat based on 'non-compliance'. At the beginning of this research, I was fully prepared to demonstrate to the clinicians that these women did not consistently follow the treatment program due to cultural differences in their explanations of GD. However, non-compliance was not an issue, much to my surprise.

The clinicians I interviewed used the term 'compliance' and placed a great deal of emphasis on it, particularly in relation to treating GD. One of the staff members explained to me that if a patient complained about altering her diet or expressed feeling deprived of food, she would tell them,

[Y]ou have diabetes now. [This diet] is better for you. You have no choice in a way to do it (LAW Interview 04/03/03).

In addition, this clinician stated that it was easy for Asian women to comply to the recommended meal plans because their diets were simple and unchanging. She said, "...they're very easy to teach because they eat the same thing" (LAW Interview 04/03/03). She used the women's logbooks as a means to determine their degree of compliance to and success in following the recommended diet. She commented, "I ask all my patients to do a food record for the first week after I see them because it does help me to see how they comply, how they understand actually" (LAW Interview 04/03/03).

Another clinician explained that the main motivation of women to comply with treatment was concern for their infant's health:

I think that they are just doing as instructed or are doing as they can, as well as they can with the instruction so that their baby is okay. I think that whether it's whomever, whatever culture, that the motivation with GD is always the outcome because it's not just the woman. It's the woman and the baby. So there is another and

there's a tremendous responsibility in that (LAW Interview 04/03/03).

For the clinicians I interviewed, compliance was directly correlated to how effective they believed they were at communicating their message and negotiating language barriers. If the women's logbooks demonstrated that their blood glucose levels were within normal range, the clinic staff assumed this meant that the women understood what they were being taught at the Clinic. One of the clinical staff told me that she was unsure if her message got across to a woman until she saw this documented proof.

One of the most revealing comments surrounding compliance came up when I asked a clinician if she found this group of ethnic women tended to follow the clinic's recommended treatment plan for managing GD:

Yes, compliance is right. What happens is that yes, because the majority of time, most women who either are, you know, unable or afraid or don't want to, or don't understand, they just don't return. They don't do the follow-up appointments (LAW Interview 04/03/03).

The high degree of compliance towards the biomedical treatment regime observed by the clinicians I interviewed may be skewed because those women who do not understand or do not agree with the plan may not return.

In relation to compliance, the women I interviewed all said that the best treatment for their GD was to explicitly follow the orders of their doctors. In addition, they all expressed gratitude towards the clinicians for helping them manage their GD. For example, Jade said through the translator, "...she happy, very, she feel that the way [clinical staff] instruct her is very helpful" (LAW Interview 11/12/02).

It is important to note that the women's responses and the high degree of compliance they demonstrated to the biomedical model's treatment regime could have been influenced by several factors. First, the women I spoke with all had successful outcomes at delivery. I did not have the opportunity to interview a woman who had experienced any negative health affects due to GD. Therefore, the experiences of a woman who may not have been happy with the treatment program set out by the Clinic may be missing in this research. Second, the women might have

associated me with the Clinic itself and they could have been worried that I would tell clinicians if they had said anything negative about the treatment regime or the staff. Third, it has been observed in transcultural nursing guides that individuals from Asian countries tend to defer to authority figures, including health care providers and researchers, like myself (Leininger 2000). When clinical staff asked these women a question or if they understood what was being said, the women may have nodded their heads in agreement whether they understood or not. This may have been done in order to save face if they could not understand what was going on or in order to not embarrass the clinicians by disregarding their advice (Leininger 2000).

One of the clinical staff I interviewed addressed this cultural pattern of communication and said:

A lot of those people, they respect the professional in front of them. So many times, if you ask, "Do you understand", they will shake their head and they may not understand so I never take a shake in the head and say they understand. They always have to tell me what it means, half a cup, one cup, and like a bowl of rice, I go with their Asian bowl and I say, "Is that half a bowl or a full bowl"? And they get to understand of all this. They are very good that way (LAW Interview 04/03/03).

This clinical staff member addressed this potential cultural misunderstanding based on acceptable communication patterns by asking the women to reiterate what had been said to ensure comprehension.

Due to culturally appropriate patterns of communication, it is possible that the women I spoke to responded to my questions in the way they thought I wanted them to, out of respect or fear. However, based on our discussions, including my observations of their body language and facial expressions, I believe that these women were genuinely grateful to the clinical staff in helping them manage their GD.

# June's Conceptualization of Gestational Diabetes

Before presenting the final conclusions derived from this research, it is important to outline the explanatory models (EM) of gestational diabetes (GD) from the perspective of Asian immigrant women because it is absent from the current literature. To accomplish this goal, I reintroduce June and her conceptualization of the condition as representative of the narratives of the three Asian women I interviewed. The following section outlines June's responses to Kleinman's (1980) eight questions proposed to elicit EMs.

# 1. What do you call the problem?

I call the problem 'gestational diabetes'. I had never heard of this condition before until my obstetrician told me I had it.

# 2. What do you think has caused the problem?

First, my older age at concept caused me to develop GD. Second, my diet has changed since I arrived in Edmonton and I am eating more meat and oily foods and less fruits and vegetables because they cost too much here. Third, my mother phoned me last year from back home and told me that she has Type II diabetes and I am worried that I am the one in the family who inherited the condition from her. All of these things probably caused me to get GD during this pregnancy.

### 3. Why do you think it started when it did?

My GD started when my obstetrician told me I had the condition. It didn't start until that time and I didn't feel any differently.

# 4. What do you think the condition does? How does it work?

I don't know how GD works in my body. I felt the same as I did before the doctor told me I had the condition. I didn't feel any symptoms and I was able to keep working at my job and taking care of my home and other children.

### 5. How severe is the condition? Will it have a short or long course?

GD is a very serious condition. I don't know when my condition will end, if ever, but when the doctor tells me that I no longer have GD, that's when I'll be cured.

6. What kind of treatment do you think you should receive? What is the desired outcome of that treatment?

The best treatment for my GD is to follow what the doctors at the Clinic tell me to do. I need to follow the diet they made for me, participate in more exercise, monitor my blood sugar levels, record information in my logbook, and attend my follow-up appointments. I think that the clinical staff have been doing a very good job in helping me manage my GD and I am very thankful. But I don't think that I should use insulin to treat my diabetes because it can hurt my baby.

The best outcome that can come from strictly following the Clinic's treatment regime is that my baby will be healthy upon delivery, that my baby will not have diabetes or develop it, and that I will be cured of GD and not develop diabetes until I am old.

# 7. What are the chief problems the condition has caused?

The biggest problem GD has caused for me is trying to follow the Clinic's treatment plan to manage my condition. It is difficult to make it to my follow-up appointments every two weeks because I have to book time off from work and because I do not drive. I have to ask my sister-in-law to drive me when my husband is not at home. Also, it is hard to eat my meals or snacks and test my blood glucose when I'm at work because I cannot take a break every two hours. It's also hard to adhere to the treatment program when I have to leave the house to run errands, like grocery shopping or paying bills, or when I go to my English as a Second Language class. All of these things make me worry.

When I go out with my friends, I feel different from them. If we go out for lunch and it's not time for me to eat yet, I have to sit and watch them eat. And I have to remember to bring all my supplies with me, including my glucose meter,

strips, logbook, and snacks. I'm always carrying around that meter! Also, it is embarrassing when I test my blood glucose levels in public. People look at me strangely. I just feel different. GD makes me feel different.

### 8. What do you fear most about the condition?

My greatest fear about GD is that my baby will be sick and will have diabetes. The months before you delivery your baby are suppose to be happy and exciting. Instead, I feel like I might be doing something wrong and that this will hurt my baby. I'm also afraid that I will not be cured of my diabetes or that I will develop it sooner than I should. Only old people have diabetes and I'm too young to have this condition. Lastly, I'm fearful of having to use insulin because it can hurt my baby or me.

It was important to provide June's conceptualization of GD, as representative of the narratives given to me by the three Asian women I interviewed, because it is missing from the literature. In comparison, the EMs of GD from the perspectives of the other two stakeholder groups, biomedical clinicians and a doctor of Traditional Chinese Medicine (TCM), are widely documented. A summary of June's EM also brings into focus the major findings of this research, especially considering that June's narrative demonstrates that non-compliance was not an issue for neither the staff of the Clinic or the Asian women they served even though their EMs of GD different dramatically in several areas.

### **Concluding Remarks**

Several conclusions can be derived from this research on the conceptualizations of gestational diabetes among the three stakeholder groups in Edmonton. First, there are problems in the Clinic that relate to the patient-education model employed to teach women about GD. This model places the responsibility of care solely on the individual patient. The effective transmission of knowledge and information becomes paramount when following this model. Clinical staff believed that they were successful in disseminating this information about self-care to Asian women. However, it became apparent to me from my observations at the Clinic, from the interviews I conducted with the women who

lived with the condition, and from my compilation of the EMs of GD among the three expert groups, that the patient-education model was not successful.

The amount of information provided by clinical staff to the women during the gestational diabetes class and follow-up appointments was immense. I found it very difficult to record and learn all the information, which included the techniques used for testing blood glucose and ketones, what constituted a serving size of food, what foods to eat, how much exercise to participate in, and when to come back for appointments. I had the benefit of knowing the language and recording the information in my field notes during each session. However, the women who participated in the same class as me had no notepads to record information and one did not speak English as her first language. The volume of information given in the limited amount of time of the class does not allow the patient education model to be effective without even considering other issues such as language or education.

It was interesting that even though clinic staff asked for my help in providing culturally appropriate health care to Asian immigrant women, they focused on how language was the only barrier to teaching these women how to manage GD, instead of the meaning surround the condition. For example, one staff member told me that she should learn the word 'hormone' in Chinese because this was how she explained to women what caused them to get GD. The assumption was that we all share the same EM of GD; we just need the right linguistic translation for the patient education model to work. However, words and concepts might not translate into different languages or they may not have the same meaning when the EMs of GD are different.

The patient-education model also assumes that compliance with the recommended treatment indicates that women understand the condition of GD and the reasons behind its management. However, the high degree of compliance observed by clinical staff and expressed by the women is misleading. Asian women's willingness to comply with the biomedical recommendations is likely a culturally preferred pattern of behaviour where authorities are deferred to and disagreement is unlikely as it could cause the women embarrassment or the health care professionals to loose face. The preference towards compliance pays off in terms of what the Asian women say and what they are willing to do. However, it is a mistake for health

care professionals to assume that compliance means that women understand the condition and suggested therapy. The emphasis of personal surveillance paramount to the patient-education model loses its efficacy in this situation.

Self-surveillance itself becomes an issue when considering the experience of Asian women with GD. The women I spoke with did not have a specific EM of GD, as compared to Biomedicine or Traditional Chinese Medicine (TCM). They had no local name for the condition, no real theory as to how it worked in the body, what it did, or what it could do to their health. In particular, they had no idea if they were still diabetic, if their children were, and if they would ever be cured. This caused them a great deal of stress and anxiety. Largely, their EMs of GD developed from what they had learned at the Clinic and then re-interpreted via their Asian-influenced epistemologies of balance and individual manifestations.

One of the most prominent experiences and serious inconveniences experienced by the women in terms of the Problem, Process, and Fear' of GD was the process of monitoring their condition and the extreme levels of self-surveillance. Surveillance was related to all the aspects of managing GD for these women, including testing their blood glucose, attending appointments, maintaining food restrictions, carrying around the meter, and regulating meal times.

In Biomedicine, GD was identified and diagnosed by protocols demanding surveillance. These included testing all women for GD at 24 to 28 weeks gestation and that the successful treatment demands self-surveillance and surveillance by the Clinic, which is done by downloading information from the women's blood glucose meters. This allows clinical staff to determine if the woman has been following the recommended treatment plan because it records when they tested, how often, and what the glucose values were. In addition, surveillance is the worst part of the illness of GD, at least if women properly follow the management regime of the Clinic. For example, one of the clinical staff said that women must understand that they have diabetes now and so they must follow the recommended diet. She continued to say that, in a way, they have no choice but to do it.

The TCM doctor also focussed on surveillance in the diagnosis of GD. In TCM, GD is diagnosed based on an external examination of the body and the display of symptoms related to the condition, which is typically caused by a

deficiency of Yin. In comparison to the biomedical approach, this form of surveillance was more dependent on the individualized woman and included deep pulse reading, urine tests, consideration of local environment, and monitoring the meridian system. Indeed, surveillance was used to design an individualized treatment program and monitor a woman's success in managing GD.

By examining GD as a socially constructed illness, that being an experienced set of symptoms and the knowledge about them, then the most severe symptom, the key aspect by which illness is experienced and from which any EM emerges, is the 'symptom' of surveillance. Broom and Whittaker (2004) discuss the 'culture of surveillance' surrounding the management of Type II diabetes and the use of moral language as another aspect of this socially experienced condition. The women I interviewed did not have a specific theory or conceptualization of GD other than what was provided by the Clinic and situated within their understanding of balance and individual manifestation. The women explained that they felt normal and did not have any symptoms, such as tiredness, dizziness, or weakness, until diagnosed by their doctors. GD did not exist for them outside of the process of surveillance once they entered the Clinic.

In addition to the patient-education model, the premise of the health promotion strategy was undermined when the nurses and dieticians used non-Asian examples, particularly in relation to diet, when teaching Asian women about GD and its management. The typical and often only example of Asian foods that the clinicians provided me during our interviews and to the women during their gestational diabetes class was rice. The clinical professionals were aware that culture influences health and healing as indicated by the fact they asked me to conduct this research to help them provide culturally appropriate health care. They also had some idea that the notions of balance, Yin and Yang, were important in Asian culture. This, however, is where their understanding about Asian culture ended. Utilizing the resources of the Multicultural Services at the Prairie Hospital could assist in diminishing this gap of information. In addition, it would be useful to have a doctor of Traditional Chinese Medicine come to the Clinic and provide an in-service on Asian foods that could replace Canadian-foodstuffs in the management of GD. Again, Multicultural Services could arrange this type of educational forum.

This is not to imply that clinical staff can simply learn about Asian culture and apply these generalizations to individuals, assuming that Asian women are one teachable group. If this were to happen, diversity within these cultural groups and variability between individuals would be relegated to the margins of care and this approach would be of little use to health care professionals or clients. While cultural in-services are valuable, the ability of clinical staff to meet patients where they are and devise an individualized and negotiated treatment plan is paramount to the successful management of GD.

The at times failure of the patient-education model and health promotions strategy demonstrates that the Clinic continues to represent Pratt's (1993) definition of a 'contact zone', a place where a dominant cultural group (health care professionals) perpetuates the status quo of unequal power relations while engaging marginalized groups, such as Asian immigrant women (Young 1982 and Taussig 1980). During my visits to the Clinic, I observed clinical staff directing classes and appointments, often not allowing time for women to ask questions or discuss their condition, and determining how best to deal with language barriers without including the women in these decisions. It was obvious that the health care professionals were the owners of expert knowledge and the women were expected to comply with their recommendations, or perhaps better said as direct orders, in the management of GD. This research demonstrated that this unequal power relation continues to exist in this Clinic in Edmonton.

Lastly, this research demonstrated problems with the ethics approval process in relation to clinically applied anthropology. In the case of this research, the ethics boards failed to recognize the power anthropological techniques and methods afford informants in directing interviews and the data collection process. They assumed that immigrant women were inherently vulnerable and powerless, particularly in their interactions with the biomedical model. Based on the assumption that they were protecting these women from sources of coercion, the limitations the boards placed on my means to collect data served to marginalize these women's experiences with GD by denying them a voice. The process of conducting this research affirmed for me that the best way to collect data is through the tried and true techniques of anthropological research, including participant observation and interviewing.

# Guidelines for Professionals assisting with Culturally Diverse Populations

At the begin of this research, clinical staff had asked for help in providing culturally appropriate prevention and treatment programs centred around GD for Asian immigrant women. Below, I suggest guidelines for health care professionals derived from this research. These guidelines may be applied to other hospital units and serve as a template for biomedical professionals working with diverse cultural populations.

# 1. Ask, ask, and ask

It is extremely important for clinical staff to engage women in a dialogue about their GD. First, culturally appropriate patterns of communication may lead health care professionals to assume that women understand the information that is being given to them. This is not necessarily the case. Staff needs to ask the women they serve to explain back what has been said to ensure comprehension. In addition, this will allow staff to gain a better understanding of how the women conceptualize their condition, which will lead to better treatment programs where a management plan that 'meets the patient where she is' can be developed. This approach has grounds in the harm reduction philosophy.

### 2. Compliance does not Indicate Understanding, Comprehension, or Agreement

Just because this group of women demonstrates a high degree of compliance in the eyes of clinical staff, this does not mean that they understand or agree with the treatment regime. This can lead to confusion, misunderstanding, and stress. Again, open, two-way communication is the best means for identifying EMs, between both parties, and then negotiating a suitable and culturally appropriate management plan.

### 3. Be cognizant of Culture

Based on their request for this research, clinical staff recognizes that culture influences health and healing and is crucial in providing the best care possible. It is important, however, for clinicians to be cognizant of their own culture. Biomedicine constitutes a cultural system of knowledge and within it is the subculture of the

Clinic. I will provide health care professionals at the Clinic with an in-service to provide them with the findings from this study. This gives me the opportunity to have them reflect on and discuss their own cultural backgrounds and those of Biomedicine and the Clinic.

In addition, health care professionals must be careful not to generalize and stereotype individuals. It is onerous to learn about cultural notions, values, and behaviours and then apply these generalizations to every patient that comes to the Clinic. High degrees of cultural and individual variability exist, especially when large groupings like "all Asian cultures" are used.

#### 4. Utilize the Explanatory Models Framework

Clinical staff can utilize the Explanatory Models (EMs) Framework at the Clinic. Staff can get and record in the medical chart women's conceptualizations of GD by using the ten questions I provided in eliciting the EMs of the three stakeholder groups for this research and related to the themes of 'Problem, Process, and Fear'. The EMs should be recorded before telling the women what to do and can be used to negotiate the treatment plan. Along with this, other information should be recorded, such as place of birth, language used at home, linguistic fluency with English, and the need for a translator at initial assessment.

#### 5. Utilize the Available Resources

Clinical staff must take advantage of the available resources at the hospital and outside of the premises. Multicultural Services of the Prairie Hospital offers translation services and can develop cultural in-services to meet the needs of patients and staff. In addition, the Multicultural Health Brokers of Edmonton are an invaluable resource. It is a co-op whose members are trained as health care professionals, either in Canada or their home locales. They also provide prenatal and postnatal care and it is especially important for immigrant women to be connected with this group. Health care professionals at the Clinic can foster this connection and the co-op continues follow-up with their clients after they are finished at the Clinic. Lastly, the Multicultural Health Brokers can provide cultural brokering to help resolve culturally based misunderstandings between Asian women and clinical

staff. Also, the Clinic and its staff should continue to support research done by medical anthropologists and other social scientists who can lend a new perspective to sometimes old problems.

#### 6. Develop Sample Diabetic Diets

Using the resources described in the previous section, the Clinic can develop sample diabetic diets based on locally used and available 'Asian' foods. Even though the sample diet would represent a generalized way of eating, which is considered 'Asian', the example could provide individual women with a departure point for incorporating their preferred foods into the recommended diet. Also, the teaching provided by clinical staff would be enhanced from having more knowledge about preferred foods, other than rice, and by using these examples in the gestational diabetes class and follow-up appointments.

#### 7. Offer Special Language Module for Gestational Diabetes Educational Classes

Clinical staff can work in conjunction with the Multicultural Services office at the Prairie Hospital and with translators to organize a special languages module for the gestational diabetes educational class. It was a suggestion made by two of the health professionals from the Clinic that I interviewed. Organizing this module to take place every two weeks would allow Asian women a greater chance to take the course in their language. In addition, this would provide these women with a chance to meet other women in a similar situation as new immigrants dealing with GD.

#### 8. Slow Down

Until a special languages module is offered, clinical staff needs to slow down when assisting Asian women. The amount of information women are given by clinical staff during the gestational diabetes class and follow-up appointments is huge, even when you understand the language. Clinical staff need to slow down and make sure that women understand the information by asking them.

#### 9. Establish a Protocol for Language Issues

The Prairie Hospital must establish and disseminate to all units a protocol to deal with language barriers. This protocol should take into consideration how to identify if a patient requires the use of a translator and how to ask the patient what she prefers in handling the situation i.e. use of a translator or family member. This would give patients a voice in how they are treated and provide them with the means of communication in order to express to clinical staff their fears, needs, expectations, and hopes.

#### 10. Consider language qualifications when hiring new staff

The ability of clinical staff to speak languages other than English would be extremely beneficial for patients. Translation by someone with diabetes education could assist in the dissemination of information. This qualification should be considered when hiring new staff.

#### 11. Provide At-Cost Supplies through the Clinic

Clinical staff needs to include in their teaching sessions information on the cost of the supplies, where to go to get them, and if insurance companies (and which ones) cover the cost of supplies. An even better solution would be for the Clinic to offer at-cost supplies program for patients of the Clinic. This could be set up through a pharmaceutical company and provided to patients.

#### 12. Provide other Means for Monitoring Blood Glucose Levels

One of the largest problems faced by women in the management of their GD was self-surveillance and circumscribing behaviours, which disrupted their daily lives. Monitoring blood glucose levels with the strips and meter was cited as one of the most inconvenient aspects of treatment. The Clinic could offer less invasive means of monitoring blood sugar for people who are afraid of pricking their fingers or phobic of needles or for those who cannot take the time to test while at work or outside the home. There are devices that look similar to a watch and record glucose levels every four hours. If an individual's blood glucose reaches a dangerous level, the device sounds an alarm. This type of device could ease some of the burden of

the self-surveillance expressed by the women in this study in the management of their GD.

#### 13. Never make assumptions!

Again, it is important to reiterate that while knowing about the customs of cultural groups is beneficial, it is dangerous to apply this generalized knowledge to individual woman, with their own unique backgrounds, personalities, and needs. Communication and understanding are the most powerful tools clinical staff have in providing culturally appropriate health care to Asian immigrant women in the prevention and treatment of GD.

#### Future Research

This research indicates other areas of potential research in understanding how to provide culturally appropriate health care to the diverse populations of Canada. First, translating the narratives of the Asian women I spoke with, while they were talking to the interpreter, from Cantonese and Mandarin would determine the degree of accuracy in what the translator explained the women thought about GD and their experience at the Clinic and what they actually said. Second, it would be interesting to track the current changes of the Clinic initiated in June 2003 and its implications for patient care in the management of GD in comparison to the methods of patient-education used during this research. Also, a study exploring what happens to the Asian women who do not return to the Clinic after their initial appointment due to fear or misunderstanding would illuminate other issues related to the efficacy of the Clinic in providing patient education.

In addition, it would be interesting to compare the results of this study to one examining how Canadian-born women conceptualize GD within the same contact zone and based on the same classes, appointments, and follow-up appointments. This could provide insights into how effective the patient-education model is when cultural barriers are not as pronounced. Also, a clinical trial testing acupuncture in conjunction with biomedical monitoring could examine the degree to which the two medical models used together can ease the burden of GD. Finally, a study on negotiating explanatory models within a medically pluralistic society, like Canada, would be invaluable and the medical system used in China could serve as an example.

In fulfillment of one of my objectives, I presented the results of my thesis research to the staff of the Diabetes Outpatient Clinic (the Clinic) at the Prairie Hospital on May 6, 2004<sup>23</sup>. I summarized my findings into a one-hour power-point presentation and the individuals who attended my talk included the three clinical staff members I interviewed, one doctor from the Clinic, the coordinator of the Multicultural Services office and a nurse from the Prairie Hospital, a representative from the Aboriginal Wellness Program at the hospital, and one public health nurse from the community.

After my presentation, several members of the audience were able to stay and to provide me with feedback and I found this to be one of the most rewarding experiences of this research process. The feedback was positive and it was exciting to hear the audience discuss implementing several of my suggested guidelines, including providing a Special Languages Module for the gestational diabetes (GD) educational class.

I returned to the Clinic to provide the staff with a copy of my power-point presentation, which summarized my research findings, as well as the bibliography from my complete thesis work on May 27, 2004. During my visit, one of the clinical staff I had interviewed and who had attended my presentation but was unable to stay afterwards to provide feedback asked to speak with me. She expressed concern over several statements I had made during my presentation where I used direct quotes from her interview and she wanted to provide clarification before my thesis research was published.

Based on the feedback she provided me concerning my presentation during my visit to the Clinic, her first concern was related to my discussion of language and the culture of communication. Based on the data I collected during my research, I found that the three clinical staff I interviewed all had different ways of negotiating language barriers. This particular staff member preferred to speak with clients in English whenever possible, where the other two clinicians

<sup>&</sup>lt;sup>23</sup> The name of the hospital where I conducted this research has been changed to protect the anonymity of participants.

used family members or an interpreter, respectively to translate when language was an issue. The quote I used to, in part, to demonstrate the variability in communicating with patients and that there was no protocol for clinical staff to implement when language barriers existed follows:

They don't speak English because they are afraid to. And then I can tell when I'm talking with them and talking to the interpreter, that I'll say something and they understand what I said. I point to them and say, 'you can understand English'...when I realize that, I really try again to communicate with them in English (LAW Interview 04/03/03).

The clinician requested that I clarify that she always ensures that individuals are able to speak English proficiently before she proceeds with their appointments. Specifically, she has each patient explain the information back to her to ensure comprehension of the material and comfort level speaking English. In addition, she told me that she never assumes that 'the nodding of the head' indicates that an individual understands what is being said to them or agrees with the information. She explained to me that she became aware of this cultural pattern of communication during her experience treating patients of diverse backgrounds and during continuing education courses. In addition, she stated that she ensures that all new staff members to the Clinic know about this pattern of communication in order to assist them in avoiding cultural misunderstandings.

Her second concern was related to my discussion of culture and diet. In my presentation, I used the following quote, which I had interpreted to mean that Asian women's diets were simple and unchanging:

Their breakfast, lunch, and supper is always the same so they're very easy to teach...it's always rice (LAW Interview 04/03/03).

The clinician told me that this was a misinterpretation of her comments. She explained that Asian women typically have a meat, starch, and vegetable with every meal and that this represents the standard composition of every meal. According to her, the foodstuffs are typically purchased at the grocery store and prepared at home. She provided further clarification by comparing this type of standardized diet with one more typical of a Canadian-born woman. She stated

that Canadian-born women often select from a variety of food options at every meal. For example, she said that a Canadian woman might have any combination of the following foods for breakfast alone: bacon, eggs, toast, a bagel, jam, frozen waffles or pancakes, hash browns or potatoes, omelettes, French toast, syrup, fruit, and yoghurt. She continued that at lunchtime, a Canadian woman might bring a packed lunch from home or she may go out for lunch or get take-out food from any number of venues, including Subway, Burger King, or McDonalds. The clinician wanted to clarify that she did not mean to say that Asian women were easier to teach because their diets were simple but rather that they tend to follow a certain standardized meal plan that she has become very familiar with during her thirty years of experience working with diabetic patients from this cultural group.

Lastly, the clinician was offended with my suggestion that the Clinic "...develop sample diabetic diets based on locally used and available 'Asian' foods" that could provide a "...departure point for women to incorporate their preferred foods into the meal plan" and provide "...dieticians with more examples, other than rice, to be used in class and follow-up appointments". She said that she was worried by how my suggestion failed to reflect her ability to assist Asian women with GD. She explained to me that she is knowledgeable about and incorporates many examples of culturally relevant 'Asian' foods into her section of the gestational diabetes educational class and in her consultations with individual clients. She explained that she has become familiar 'Asian' foods during her 30 years of practice and she explained to me that patients appreciate it when she can discuss their preferred foods, such as Kim chi, during their sessions.

My intention in presenting my results to staff and making the comments I did, including my suggested guidelines for practitioners working with culturally diverse populations, was not to imply that the Clinic or its staff members are not making these efforts in their daily practice. In addition, my findings are not based solely on what this one clinician told me but are a compilation of information gathered from various sources, including the Asian women I interviewed and what they had to say about their experiences with GD, my observations at the Clinic, and the available literature. Particular quotes were used to demonstrate a point or finding from my research in a condensed and concise manner.

The suggested guidelines I proposed to practitioners working with culturally diverse populations are particularly relevant to the Clinic but are also generalized for a larger audience. For example, my suggestion to develop sample diabetic diets based on locally available 'Asian' foods is for the benefit of new clinicians who may not have the experience or training of the clinician that I had interviewed. Also, it can be used as a starting point for other diabetes outpatient clinics and hospital units in Canada that are struggling with these kinds of issues when providing care to a diverse population.

From an anthropological perspective, it is important to point out that informants want to 'put their best face forward', like we all do, and it can be difficult to hear your own words read back to you as a direct quote. What a person says and how a person talks in conversation can be very different from how they would present the same information in written form with the option of reviewing and editing their statements. This exercise may have made the clinician uncomfortable with what she had said and how I represented her voice. In addition, what people say and what they do are not always the same.

This situation further illuminates the problem with the restricted access I had to the Clinic based on the stipulations of the ethics boards and how I was denied the tool of participant observation in the collection of data for this research. First, the limitations the boards placed on my means to collect data served to marginalize Asian women's experiences with GD by denying them a voice because the members assumed that these women were inherently vulnerable and powerless, particularly in their interactions with the biomedical model and with myself, as a researcher. Second, the clinician's concern that my findings did not accurately reflect her role at the Clinic demonstrates how important participant observation is to further contextualize informant's statements by observing when their actions are consistent with their statements. The tool of participant observation is invaluable for this type of research and has the advantage of providing texture to a complex social and cultural experience, such as living with GD or assisting those with the condition. I believe the staff of the Clinic have been and are continuing to provide the highest standard of care to their clients and that patient care is their number one priority. This statement is based on my interviews with clinical staff, my observations at the

Clinic, and most importantly, based on what the women with the condition told me about the Clinic's staff and the treatment they received. They expressed to me that they were extremely grateful and very happy with the way clinical staff helped them manage their GD. It is obvious to me how committed the Clinic is to culturally diverse care and its importance in successfully managing GD.

#### **Bibliography**

#### American Diabetes Association

1997 Gestational Diabetes: What to Expect. 3<sup>rd</sup> Edition. Alexandria, Virgina: American Diabetes Association.

#### Broom, Dorothy and Andrea Whittaker

2004 "Controlling Diabetes, Controlling Diabetics: Moral Language in the Management of Diabetes Type 2". Social Science & Medicine 58: 2371-2382.

#### Bourdieu, Pierre

1990 The Logic of Practice. California: Stanford University Press.

#### Capital Health Authority

2004 Programs and Services: Women's Health". Capital Health Authority Online, http://www.capitalhealth.ca/Health+Services/Hospitals/Royal+Alexandra+Hospital/Programs+and+Services/Womens+Health.htm; accessed 14 April 2004.

#### Canadian Diabetes Association

2004 "Diabetes Facts". Canadian Diabetes Association Online, http://www.diabetes.ca/Section\_About/thefacts.asp#types; accessed 14 April 2004.

### Cohen, M.Z., T. Tripp-Reimer, C. Smith, B. Sorofman, and S. Lively

1994 "Explanatory Models of Diabetes: Patient Practitioner Variation". Social Science and Medicine 38: 59-66.

#### Comaroff, Jean

1988 "The Diseased Heart of Africa: Medicine, Colonialism and the Black Body". In *Analysis in Medical Anthropology* S. Lindenbaum and M. Lock, eds. Netherlands: Dordrecht: D. Reidel.

#### Creswell, John W.

1994 Qualitative and Quantitative Approaches. Thousand Oaks, California: SAGE Publications.

#### Daley, T.C. and T.S. Weisner

2003 "I Speak a Different Dialect: Teen Explanatory Models of Difference and Disability". *Medical Anthropology Quarterly* 17(1): 25-48.

#### Diabetes Outpatient Clinic

1986 "The Final Proposal", available from the Diabetes Outpatient Clinic.

Dunbar, Peggy

"Gestational Diabetes: Special Delivery." Canadian Diabetes Association Online, http://www.diabetes.ca/Section\_About/gestational.asp; Date of original submission Summer 1996. Revised June 2001; accessed 14 April 2004.

Ehling, Dagmar

2001 "Oriental Medicine: An Introduction". Alternative Therapies 7(4): 71-82

Ehling, Dagmar and Katie Singer

1999 "Gauging a Woman's Health by her Fertility Signals: Integrating Western with Traditional Chinese Medical Observations". *Alternative Therapies* 5(6): 70-83.

Evans-Pritchard, E.E.

1976 Witchcraft, Oracles, and Magic among the Azande. Oxford: Clarendon Press.

Fadiman, Anne

1997 The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors and the Collusion of Two Cultures. New York: Farrar, Straus, and Giroux.

Foster, George M.

1998 "Disease Etiologies in Non-Western Medical Systems". In *Understanding and Applying Medical Anthropology*. Peter J. Brown, ed. Toronto: Mayfield Publishing Company, pp. 110-117.

Foucault, Michel

1973 The Birth of the Clinic. London: Tavistock.

Geertz, Clifford

1973 The Interpretation of Cultures: Selected Essays. New York: Basic Books.

Good, Byron

1994 Medicine, Rationality, and Experience: An Anthropological Perspective. New York: Cambridge University Press.

Gordon, Deborah

1988 "Tenacious Assumptions in Western Medicine". In *Biomedicine Examined*. Margaret Lock and Deborah Gordon, eds. Boston: Kluwer Academic Publishers, pp. 19-56.

Gould-Martin, Katherine

1978 "Hot Cold Clean Poison and Dirt: Chinese Folk Medical Categories". Social Science and Medicine 12: 39-46.

#### Hare, John W. and Florence M. Brown

1995 "Pathophysiology". In *Diabetes Complicating Pregnancy: The Joslin Clinic Method.* 2<sup>nd</sup> Edition. Florence M. Brown and John W. Hare (eds.). New York: Wiley-Liss, pp. 3-14.

#### Health Research Ethics Board of the Capital Health Authority

2004 "About the HREB". Health Research Ethics Board Online, http://www.capitalhealth.ca/Research/Health+Research+Ethics+Board/Health\_Research\_ethics\_Board.htm; accessed 14 April 2004.

#### Hodgson, I.

2000 Culture, Meaning, and Perceptions: Explanatory Models and the Delivery of HIV Care. Abstract MoPeD2772, XIIIth International AIDS Conference, Durban, South Africa, July 14th-19th. Available online http://www.bradford.ac.uk/staff/ijhodgson/summaries/Publication s/durban2000.htm; accessed 14 April 2004.

#### Huyen-Thanh Vu, Helen

1996 "Cultural Barriers between Obstetrician-Gynecologists and Vietnamese/Chinese Immigrant Women". Texas Medicine 92(10): 47-52.

#### Jarvis, Gerald Joseph

1994 Obstetrics and Gynaecology: A Critical Approach to the Clinical Problems. New York: Oxford University Press.

#### Jenkins, Richard

2002 Pierre Bourdieu. Revised Edition. New York: Routledge

#### Joralemon, Donald

1999 Exploring Medical Anthropology. Toronto: Allyn and Bacon.

#### Kleinman, Arthur

1988 The Illness Narratives: Suffering, Healing and the Human Condition. New York: Basic Books.

#### Kleinman, Arthur

1980 Patients and Healers in the Context of Culture. Los Angeles: University of California Press.

#### Larme, Anne C. and J.A. Pugh

1998 "Attitudes of Primary Care Providers Toward Diabetes: Barriers to Guideline Implementation". *Diabetes Care* 21(9): 1391-1396.

#### Lee-Parritz and Heffner

1995 "Gestational Diabetes". *Diabetes Complicating Pregnancy: The Joslin Clinic Method.* 2<sup>nd</sup> Edition. Florence M. Brown and John W. Hare (eds.). New York: Wiley-Liss, pp. 15-40.

#### Leininger, M.

1991 Culture Care Diversity and Universality: A Theory of Nursing. New York: National League for Nursing.

#### Leslie, Charles

1977 "Pluralism and Integration in the Indian and Chinese Medical System". In *Culture, Disease and Healing*. D. Landy (ed). New York: Macmillan, pp. 511-518.

#### Li, W.L., H.C. Zheng, J. Bukuru, and N. De Kimpe

2004 "Natural Medicines used in the Traditional Chinese Medical System for the Therapy of Diabetes Mellitus". *Journal of Ethnopharmacology* 92: 1-21.

#### Lock, Margaret and Deborah Gordon

1988 "Relationship between Society, Culture and Biomedicine: An Introduction to the Essays". In *Biomedicine Examined*. Margaret Lock and Deborah Gordon, eds. Boston: Kluwer Academic Publishers, pp. 11-16.

#### Loewe, Ron and Joshua Freeman

2000 "Interpreting Diabetes Mellitus: Differences between Patient and Provider Models of Disease and their Implications for Clinical Practice". *Culture, Medicine, and Psychiatry* 24: 379-401.

#### Mahidhassan, S.

"Comparing Yin-Yang, the Chinese Symbol of Creation, with Ouroboros of Greek Alchemy". *American Journal of Chinese Medicine* XVII(3-4): 95-98.

#### Palinkas, LA., E. Prussing, J. Landsverk, and V. Reznik

2003 "Youth-Violence Prevention in the Aftermath of the San Diego East Country School Shootings: A Qualitative Assessment of Community Explanatory Models". *Ambulatory Pediatrics* 3(5): 246-252.

#### Penas-Lledo, E, F.J. Vaz Leal, and G. Waller

2002 "Excessive Exercise in Anorexia Nervosa and Bulimia Nervosa: Relation to Eating Characteristics and General Psychopathology". *Issues in Mental Health Nursing* 23(2): 91-105.

#### Peterson, J.W., Y.M. Sterling, and J.W. Stout

2002 "Explanatory Models of Asthma from African-American Caregivers of Children with Asthma". *Journal of Asthma* 39(7): 577-590.

Pratt, Mary Louise

1993 Imperial Eyes: Travel Writing and Transculturation. New York: Routledge.

Rivers, William H.R.

1927 Magic, Medicine and Religion. London: Routledge and Kegan Paul.

Reece and Coustan

1988 "Preface". In *Diabetes Mellitus in Pregnancy: Principles and Practice*. E. Albert Reece and Donald R. Coustan (eds.). New York: Churchill Livingstone, pp. xiii-xiv.

Reifsnider, E. and Allan J. Percy

2000 "Mother's Explanatory Models of Lack of Child Growth". *Public Health Nursing* 17(6): 434-442.

Reinharz, Shulamit

1992 Feminist Methods in Social Research. New York: Oxford University Press.

Roper, Janice and Jill Shapira

2000 Ethnography in Nursing Research. Thousand Oaks, California: Sage Publications.

Sathyaseelan, M., R. Jayakaran, C. Vijayakumar, S. Muthurathnam, and K.S. Jacob 2003 "Explanatory Models of Psychosis among Community Health Workers in South India". *Acta Psychiatrica Scandinavica* 108(1): 66-69.

Scheper-Hughes, Nancy

1992 Death without Weeping: The Violence of Everyday Life in Brazil. Berkeley: University of California Press.

Schreiber, R., and G. Hartrick

2002 "Keeping it Together: How Women use the Biomedical Explanatory Model to Manage the Stigma of Depression". *Issues in Mental Health Nursing* 23(2): 91-105.

Smith, H.W.

1981 Strategies of Social Research: The Methodological Imagination. 2<sup>nd</sup> Edition. New Jersey: Prentice-Hall, Inc.

Snell, L., R.P. Wilson, K.C. Oeffinger, C. Sargent, O. Chen, and K.M. Corey
2002 "Patient and Physician Explanatory Models for Acute Bronchitis".

\*\*Journal of Family Practice\*\* December 2002.

Tang, Zongli

1995 "Confucianism, Chinese Culture, and Reproductive Behavior".

Population and Environment: A Journal of Interdisciplinary Studies 16(3): 269-284.

Taussig, M.T.

1980 "Reification and the Consciousness of the Patient". Social Sciences and Medicine 14: 3-13.

Young, Allan

1982 "Rational Men and the Explanatory Model Approach". Culture, Medicine, and Psychiatry 6: 21-34.

Young Leslie, Heather

2001 Personal Communication. Edmonton: University of Alberta, 15 May 2001

Zhong Yin Zhou and Jin Hui De

1997 Clinical Manual of Chinese Herbal Medicine and Acupuncture. New York: Churchill Livingston.

#### Health Research Ethics Board of the Capital Health Authority Ethics Statement and Approval

#### SECTION A: GENERAL INFORMATION

A1. Project Title

Title of Project: The Socioeconomic and Cultural Contexts of 'Asian'					
Immigrant Women with Gestational Diabetes: A Case Study at the					
Prairie Hospital in			•		
A2. Applicant Inf	ormation				
Name: Lisa	Wozniak		and the control of th		
Title: MA	Candidate				
Department: Anth	ropology (Univer	sity of Alberta)			
Mailing Address: 13	-15 HM Tory Bui	lding			
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Province:	Code:	(780) 492-3879	(780) 492-5273		
Edmonton,	T6G 2H4				
Alberta					
E-mail Address: lw	ozniak@hotmail.	com			
Signature:			Date: <b>January 4, 2002</b>		
L			<u> </u>		
A3. Co-Applicant	Information				
Name:					
Title: Not Applicable					
Department:					
Mailing Address:					
City &		Phone:	Fax:		
Province:	Code:				
E-mail Address:					
Signature:			Date:		

<sup>&</sup>lt;sup>24</sup> In my original ethics application, the hospital name was included. It has been changed here to retain participant anonymity.

A4. Authorizing Signature			
Indication of Department Support for the Implementation of	the Project.		
Name of Dept. Chair, Assoc. Dean of Research, or Supervisor:			
Dr. Heather Young Leslie			
Title: Assistant Professor			
Signature: Please see attached letter of support	Date:		
	January 4, 2002		

raduate thesis? (X) Yes		
the hames, departments, and	phone numbers of your thesis	
Department/Program:	Phone:	
Anthropology	(780) 492-0137	
Anthropology	(780) 492-9879	
	Department/Program:  Anthropology	

A6	. Expedited Review
If	the study procedures are <b>LIMITED</b> to any of the following, please check ( $$ ):
	Analysis of blood, urine, or any other biological specimen already collected.
X	Examination of patient, medical, or institutional records.
	Modification of a previously approved protocol (specify title and approval date):
	Secondary analysis of data.
	Use of biological specimens normally discarded.

A7. Type of Investigation				
Which one of the following best desc	ribes the	type of investigation proposed?		
Check $()$ more than one if appropriate.				
Clinical Trial		Multi-centre Trial		
Drug Study		Pilot Study		
Epidemiological Study	X	Qualitative Study		
First Application in Humans		Technology Assessment /		
		Development		
Sequel to Previously Approved P	Sequel to Previously Approved Project (specify title and approval date):			
Other (specify):	Other (specify):			

A8. Site of Research				
Where will the research be conducted? Check $()$ more than one if appropriate.				
Specify the area/department/program.				
Alberta Cancer Board Sites:				
Cross Cancer Institute:				
Capital Health Authority Sites:				
X Prairie Hospital: Diabetes Outpatient Clinic				
Caritas Health Group Sites:				
Edmonton General Hospital:				
Grey Nuns Community Hospital and Health Centre:				
Misericordia Community Hospital and Health Centre:				
University of Alberta Sites:				
Specify (e.g. Corbett Clinic):				
Other:				
Specify (e.g. Edmonton Public Schools, Subjects' homes):				
Letters of Support: Dr. Bill Jones and Dr. Heather Young Leslie <sup>25</sup>				
( ) Pending (X) Attached ( ) Not Applicable				

A9. Funding / Budget					
How is t	How is the project funded? Please check ( $$ ) the appropriate box.				
	Funding approved; specify source(s):				
	Funding pending; specify source(s):				
X	No external funding required.				
Budget					
N/A	Please check here $()$ that you have attached a budget summary. The summary must include details of investigator payments and recruitment incentives (if present). Please attach the budget as an appendix to the				
	form.				

<sup>&</sup>lt;sup>25</sup> Pseudonyms have been used for all proper names excluding those of my supervisors and myself.

A10. R	emuneration **			
Are any	of the investigators involved receiving any directs personal remuneration or			
other personal or family financial benefits (either direct or indirect) for taking part in				
this inv	estigation?			
	Yes. If so, append a letter detailing these activities. Please attach this letter			
	to your budget summary.			
X	No			

A11. Safety Approvals						
Please check ( $$ ) whether or not this study requires any of the following safety approvals. If a safety approval is needed, please indicate whether the approval documentation is pending or attached as an appendix to this form.						
	nazardous Materials:					
X	Not Applicable	P	ending		Attached	
Elec	Electromechanical:					
X	Not Applicable	P	ending		Attached	
Health Protection Branch or Other Canadian Federal Agency:						
X	Not Applicable	P	ending		Attached	
Radiation:						
X	Not Applicable	P	ending		Attached	

#### **SECTION B: DETAILS OF PROJECT**

#### Description of the Project

### B1. Provide a clear statement of the purpose and objectives of the project.

Health practitioners at the Prairie Hospital report a high percentage of Chinese immigrant women being admitted for treatment of gestational diabetes. While the commitment of the hospital to issues of multiculturalism in relation to health care is strong, the medical staff at the Diabetes Outpatient Clinic have identified gaps in social and cultural information available on Chinese immigrant women in this locale and, therefore, lack the means to support these women and design programs to prevent future occurrences. The objective of this research project is to apply the techniques of clinical anthropology, as developed by Kleinman (1980), to elicit information necessary for understanding the unique social, economical and cultural determinants of health among this ethnic and immigrant group in Edmonton. This information will assist medical practitioners at the Prairie Hospital in negotiating the management of gestational diabetes among this ethnic group.

#### B2. State the hypotheses and/or research questions.

The researcher hypothesizes that the onset and subsequent management of gestational diabetes among Chinese immigrant women is affected by their cultural perceptions concerning health and wellness and by their socioeconomic position related to their status as immigrants. Specifically, the research questions to be addressed by this project include:

- 1. What are the risk factors for gestational diabetes and does the incidence of gestational diabetes among Chinese women differ from other ethnic groups?
- 2. What constitutes a normal pregnancy and how is gestational diabetes perceived and treated in the origin locales of the Asian migrants (i.e. China, Vietnam, Japan, Laos, Thailand, etc.)? What are the various cultural perceptions surrounding the state of pregnancy and difficulties, which may arise during pregnancy, and how do these differ from each other?
- 3. After accounting for genetic predisposition and baseline weight (BMI), what underlying factors (social, economic, and cultural) affect 'Asian' immigrant women's health in regards to the development and management of gestational diabetes as well as their ability to access health care?

## B3. Briefly summarize past human and/or animal research that has lead to this project.

Gestational diabetes occurs in three to five percent of all pregnancies in the Canadian population. In other words, one in twenty pregnant women will develop this type of diabetes (Canadian Diabetes Association 2001). Risks associated with

gestational diabetes for the mother include the increased possibility of "delivery by cesarean section, increased urinary tract infections, and the development of pregnancy-induced high blood pressure" (Canadian Diabetes Association 2001). The risks to the infant include macrosomia (obese birth weight), birth trauma, and neonatal hypoglycemia. Long-range implications of gestational diabetes on infants are an increased risk for "obesity and diabetes, prolonged newborn jaundice, low blood calcium, and respiratory distress syndrome" (Canadian Diabetes Association 2001).

Primary prevention of gestational diabetes involves maintaining an adequate diet, including the reduction of obesity, and participating in appropriate levels of physical activity (Health Canada 2001). Secondary prevention of gestational diabetes "involves early identification of diabetes through screening to prevent or delay the progression of the disease" (Health Canada 2001). In typical pregnancies, a physician will order screening for gestational diabetes between 24 and 28 weeks into pregnancy. However, those women who are at greater risk for developing gestational diabetes are screened earlier. As outlined by the Canadian Diabetes Association (2001), women at greater risk for developing gestational diabetes have one or more of the following factors: a family history of diabetes in a first degree relative, gestational diabetes in a previous pregnancy, the presence of a birth defect in a previous pregnancy, obesity, older maternal age, previous stillbirth or spontaneous miscarriage, a previous heavy for-dates infant, and/or a history of pregnancy induced high blood pressure, urinary tract infections, or hydramnios.

Treatment of gestational diabetes typically includes testing blood sugar levels, eating a healthy diet, and participating in regular physical activity. In some cases, women are required to take insulin as part of their treatment plan (National Institute of Child Health and Human Development 2001). This treatment of gestational diabetes in the general population has been shown to be effective. However, health care providers at the Prairie Hospital Diabetes Outpatient Clinic have expressed a desire to learn more about the incidence, perception, and responses to gestational diabetes in order to improve upon the health of a particular portion of their client population, women identified as Asian and immigrant.

Several scholars within the fields of biomedicine and the social sciences have concluded that social factors related to immigrant status may negatively impact the health of immigrants (Anderson 1998, 1996, and 1987; Anderson et al. 1991 and 1991; Chen et al. 1996; DeSantis and Halberstein 1991; Frisbie et al. 2001; Gannage 1996; Grossi et al. 1999; Hanna 1997; Lew 2001; Lock 1992; Payer 1988; Pernice and Brook 1994; Sherwin 1992; and Xueqin 1999). For example, studies suggest that many immigrants encounter language barriers, a decline in socioeconomic status, and a lack of necessary social networks in Canada, which can hinder wellness (Frisbie et al. 2001; Anderson 1998, 1996, and 1987; and Lock 1992). A recent study demonstrates that the health of immigrants in fact deteriorates based on duration of stay in their new Western country (Frisbie et al. 2001).

The diverse literature addressing the experience of various immigrant groups in North America and the trend of declining health in relation to negative social and economic factors seems to be replicated in Edmonton, despite the commitment to multicultural health care and a dedication to providing comprehensive care by health practitioners at the Diabetes Outpatient Clinic. In comparable situations elsewhere, clinical anthropological methods have been proved helpful in dealing with the compelling social, economic and cultural contexts, which overlap with what seem to be higher than normal gestational diabetes rates among Asian immigrant women in Edmonton. In response to the request of health practitioners at the Prairie Hospital, it is anticipated that this research will assist medical professionals and Asian immigrant women in the negotiation and management of gestational diabetes.

#### Description of Sample/Population

B4. Describe the numbers and type(s) of subjects to be included. If appropriate, specify the number of subjects in each study group. Provide a rationale for the sample size and include sample size calculations where appropriate.

The selection criteria for informants include self-selected and voluntary participation. I anticipate a type of 'snowball' effect for participation in this research program as women I interview may introduce someone else she knows to this study. Therefore, specifying an exact number of subjects to be included in this study group is not suitable at this time.

#### B5. List any subject inclusion/exclusion criteria.

All subjects to be recruited will be Asian immigrant women of childbearing age with gestational diabetes who are currently using the services of the OutPatient Diabetes Centre at the Prairie Hospital. According to the GFC Policy Manual, Section 66, "University of Alberta Standards for the Protection of Human Research Participants", all researchers must ensure "high ethical obligations towards vulnerable persons - to those whose lack of competence or decision-making capacity renders them vulnerable". Therefore, no children or institutionalized persons will be included in this research project.

### B6. Please check $(\sqrt{})$ if any of the subjects who will be recruited fall into one or more of the following categories:

	Under 18 years of age
	Cognitively Impaired
	Residing in institutions (e.g. prison, extended care facility)
	Students
	Employees of researchers' organization
X	Have language barriers (e.g. illiterate, not English-speaking, dysphasic)
	In another country

#### **Description of Research Procedures**

B7. Provide a summary of the design and procedures of the research. Provide details on the methods of data collection and data analysis, time commitment for the subjects etc. Please note that any and all study measures need to be appended to the copies of the research / grant proposal (e.g. questionnaire, interview guides, rating scales etc.).

Previous to the ethics review of this research project, a literature review was conducted on the social factors related to immigrant status, which can negatively affect immigrant health. Currently, an on-going literature search related to the risk factors of gestational diabetes and its rate of occurrence between ethnic groups is being conducted. In order to answer the research questions outlined in section B2, ethnographic fieldwork will be conducted at the Prairie Hospital. This fieldwork will include three different components: retrospective chart review, observation in the clinic, and open-ended, multiply triangulated (follow-up) interviews.

- 1. Chart review: A review of each patient's medical charts will provide baseline information on the informant's medical history, documentation of conception date, first appointment in regards to pregnancy, as well as documentation of interactions with the medical staff at the Prairie Hospital in relation to gestational diabetes. Language spoken and immigrant status may also be identified from the chart and provide initial estimates of the cultural variety of the population and length of time in Canada. This information is critical for the analysis of when and how Asian immigrant women seek health care, especially in relation to pregnancy.
- 2. Observation: With the consent of informants, as well as the clinic personnel and with due regard to confidentiality, the researcher (Lisa Wozniak, MA candidate) may attend clinic sessions. The most appropriate means to facilitate consent in regards to these observations would be to ask the women who have agreed to be interviewed if I could also sit in on their clinic sessions. In the interview setting, the women will have already been informed about the study, provided consent for the interview, and will understand the issues surrounding confidentiality and their right to withdraw from the study. All participants will be informed of their right to decline the researcher's participation in this aspect of their clinical care. In addition, it will be made explicit that informants can withdraw their consent allowing the researcher to attend their clinical sessions at any time during the study.
- 3. Interviews: The researcher (Lisa Wozniak, MA candidate) will conduct one on one, open-ended, confidential interviews with women to be recruited initially by a nurse or receptionist. The interviews will be staggered and each will take approximately one hour. An estimated four interviews will be requested of each participant. As well, and according to their willingness, the researcher may conduct interviews with clinic staff. All interviewees will be asked to sign a consent waiver (see section B10).

The emphasis of interviews will be to allow the informants to freely discuss their

perceptions of their condition and their concerns in regards to their health care. The guiding interview questions are attached at the end of this document. When needed, language interpreters will be provided by Multicultural Services at the Prairie Hospital (contact person is Ann Web). Interview subjects will focus primarily on the women's perception of their condition, concerns about health care and services, duration of time in Canada, and socioeconomic status in relation to their health seeking strategies. With participants' consent, each interview will be documented on audiotapes, copies of which will be made available to the participants of this research project. Based on information collected during the preliminary interviews, the guiding questions will be re-focused to address the concerns facing Asian immigrant women.

- 4. Data Analysis: Data will be catologued and analyzed thematically and correlated with academic and clinical literature on Asian and immigrant health. A report from the results of the research will be presented to the staff of the Diabetes Outpatient Clinic and Multicultural Program at the Prairie Hospital.
- B8. Which treatments or procedures are additional to those required for standard patient care?

Not Applicable

B9. If the procedures include a blind, under what conditions will the code be broken and what provisions have been made for this? Who will have the code?

Not Applicable

#### **Obtaining Consent**

B10. Clearly detail who will be recruiting subjects and obtaining consent, and the procedures for doing this. If appropriate specify whether subjects will be randomly assigned to groups before or after consent has been attained.

A nurse or receptionist will approach potential informants at the Prairie Hospital Diabetes Outpatient Clinic. During this initial contact, the translator will inform possible participants in the language of their choice of the research objectives of this study and that their decision to participate will have no consequences on their health care. Any informants interested in participating will be explicitly informed by myself (Lisa Wozniak, MA candidate), through the use of a translator if required, of my status as a researcher, the objectives of my research and the methods I propose to use, and how I plan to use the data collected (i.e. academic publications).

The Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans insists that researchers respect the "exercise of individual consent". Therefore, each participant in this research project will be explicitly informed of my

status as a researcher, the purpose and methodology of the study, as well as my intention to publish research results in academic forums. In addition, all participants will be advised that they may withdraw from the project at anytime during the project, including during the interviewing process. Also, informants will be notified that their participatory status in the research project will not be communicated to any health practitioners. After being informed of the research objectives and prior to conducting interviews, the participants will be asked to sign a Participant Consent form which I will review with each individual (with the assistance of an interpreter, if needed) that outlines the above information.

Subjects will not be assigned into groups before or after consent has been attained and, therefore, this topic is not applicable to this ethics review application.

B11. Specify methods for dealing with groups identified in #B6. If the subjects are not able/competent to give fully informed consent, who will consent on their behalf?

As all informants for this research project will be of Asian immigrant status, potential language barriers in relation to informed consent must be addressed. A translator will be provided for all non-English speaking participants or those who prefer to use their first language. Upon informing the participants of the objectives, methods, and possible publication of the research project and reviewing the consent form in the language of their choice, each informant will be asked to sign a consent form.

B12. If the subjects will be offered compensation for participating in the research, provide details. Specify the amount, what the compensation is for, and how payment will be determined for subjects who do not complete the study.

Not Applicable

B13. Do any of the procedures include the use of deception or partial disclosure of information to subjects? If yes, provide rationale for the deception or partial disclosure. Describe the procedures for (a) debriefing the subjects and (b) giving them a second opportunity to consent to participate after debriefing.

No

Recruitment Aids/Information Letters/Consent Forms					
B14. Are you planning to use any recruitment aids such as posters, newspaper advertisements, radio announcements, or letters of invitation? If so, please indicate the reading level of each aid and check ( $$ ) if it has been attached to the form as an appendix.					
Recruitment of informants will be based on referrals from a nurse or receptionist of the Diabetes Outpatient Clinic at the Prairie Hospital and possible referrals from interviewees. Therefore, no recruitment aids will be employed. However, all informants will be asked to sign a consent form, which is attached at the end of this document.					
Recruitment Aid #1 – Specify (e.g. poster, letter etc.):					
X Not Applicable	Reading Level	Attached			
Recruitment Aid #2 – Specify:					
X Not Applicable	Reading Level	Attached			
Information Letter #1 – Specify (e.g. Letter for interviews, focus groups etc.):					
X Not Applicable	Reading Level	Attached			
Information Letter #2 – Specify:					
X Not Applicable	Reading Level	Attached			
Consent Form #1 – Specify (e.g. Consent for interview, focus group etc.):  A consent form for participating in interviews will be signed by all					
	informants. This is in accordance with the Tri-Council Policy Statement that				
demands respect for the free and informed consent of all human research					

Reading Level

X

Attached

participants.

Not Applicable

# B15. What steps have been taken to make the recruitment aids, information letters, and consent forms comprehensible to the person(s) giving consent?

A translator will be provided to informants to ensure that the consent form is comprehensible to each participant in their preferred language. In addition, the researcher (Lisa Wozniak, MA candidate) will conduct background research concerning culturally acceptable interviewing techniques.

#### **Risks and Benefits**

### B16. What are the benefits of the proposed research for the subject and/or for scientific knowledge in general?

#### Benefits to 'Asian' immigrant women:

- Provides them the opportunity to discuss their fears and hopes about their pregnancy in a context, which is less power-laden than that characterized by the clinical setting.
- Eliciting women's explanatory model for their gestational diabetes may enhance teaching and eventual acceptance of medical recommendations.
- Potential to improve their health care and that of other women of the immigrant and 'Asian' community.
- Introduces their cultural concepts and their voices into the corpus of local health services information.
- Expanded communication has the potential to enhance the entire peri-natal experience.

#### Benefits for the Child (unborn/infant):

- Reduced potential for peri-natal risks (i.e. macrosomia, birth trauma, and neonatal hypoglycemia) and for later problems (i.e. increased risk for obesity and diabetes, prolonged newborn jaundice, low blood calcium, and respiratory distress syndrome) if mothers in the study follow medical recommendations more closely during pregnancy.
- Potential to normalize pediatric services from at-risk child to healthy baby care.

#### Benefits to the Staff at the Prairie Hospital:

- Facilitates clinic staff in their roles as health care providers.
- Supports the commitment of hospital staff to incorporate cultural identity, values, and practices in health services by strengthening cultural responsiveness
- Promotes dialogue between and among patients and health care providers.

#### Benefits to Academia:

 Documenting relationship of culture and health, in a local and Canadianspecific context.

- Augment and expand anthropological research demonstrating the potential impact of immigrant status to the health of newcomers.
- Demonstrate methodology and benefits of clinically applied anthropology to patients and medical practitioners.
- Provide baseline ethnographic data about various 'Asian' immigrant women in Edmonton.

B17. What adverse effects may result from the research? How will adverse effects be dealt with? Please note that adverse effects are not limited to physical risks, but include psychological, emotional, and spiritual risks as well.

I anticipate no adverse effects to be encountered by the research informants, which would be any worse than their current clinical experience, and the potential for benefit outweighs the potential risks. If any, potential risks could be of a psychological nature, such as concern about invasion of privacy or embarrassment. However, the research design follows the "Tri-Council Policy Statement - Ethical Conduct for Research Involving Humans". These guidelines ensure the cultural, physical, and psychological integrity of all participants. All research participants will be explicitly informed in writing and verbally, with an interpreter if necessary, of the nature of this research, their right to free and informed consent, their right to withdraw from the study at anytime, and that their privacy will be protected.

#### Privacy and Confidentiality

### B18. What steps will be taken to respect the privacy of the subjects and protect confidential data?

Participants will be explicitly informed of the nature of this research project and their rights as participants (see section B17), in writing, and/or verbally with an interpreter if necessary. All informants will be made aware of their right to anonymity. To ensure this, pseudonyms will be used. In addition, participants' privacy will not be invaded during the interview process. If the participant seems or expresses reluctance to continue, the interview will be terminated immediately, and/or rescheduled for another time.

### B19. Identify any agencies or individuals who will have access to confidential data now or in the future.

Participants will be told that clinic staff will receive a report outlining the results of this project. The same report will be made available on request to local community organizations such as Catholic Social Services and the Edmonton Mennonite Centre for Newcomers. In addition, a thesis will be produced which will be read by the committee members and which will be available, on request, to the academic community. Finally, the results could be published from scholarly reasons.

B20. Do you anticipate any secondary analysis of the data? Please note that any secondary analysis requires further research ethics approval.

Due to the relevance of this research project to the health of Asian immigrant women in general, the researcher anticipates that future secondary analysis of some of the ethnographic data, for a related or different anthropological project is possible, but at this point, unknowable. The need for further ethics approval is noted.

Health Research Ethics Board

biomedical research

health research

2D2.27 Walter Mackenzie Cemre University of Alberta, Edmanton, Alberta T6G 2R7 p.780.492.9724 [780.492.7503] ethics@med.nalberta.ca 3-48 Corbert Hull, University of Alberta Edmonton, Alberta T6G-2G4 p.780,492,0839 f.780,492,1626 ethics@www.rehabmed.nalberta.ca

#### UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES, CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

#### HEALTH RESEARCH ETHICS APPROVAL

Date: March 2002 Ms. Lisa Wozniak Name of Applicant: Organization: University of Alberta Department: Graduate Studies; Anthropology Name of Supervisor: Dr. Roderick Wilson Organization: University of Alberta Department: Anthropology Project Title: The Socio-economic and Cultural Contexts of "Asian" Immigrant Women with Gestational Diabetes: A Case Study at the Royal Alexandra Hospital in Edmonton, Alberta

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form.

The deliberations of the HREB included all elements described in Section 50 of the *Health Information Act*, and found the study to be in compliance with all the applicable requirements of the Act.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Dr. Sharon Warren

Chair of the Health Research Ethics Board (B: Health Research)

File number: B-130102-ANTHRO







#### Appendix 2

#### Department of Anthropology Ethics Advisory Group Statement and Approval

Lisa Wozniak MA Candidate Department of Anthropology University of Alberta

#### **SECTION A: General Information**

**Research Title:** The Socioeconomic and Cultural Contexts of Chinese Immigrant Women with Gestational Diabetes: A Case Study at the Prairie Hospital in Edmonton, Alberta<sup>26</sup>

#### Purpose of the Research

Health practitioners at the Prairie Hospital report a high percentage of women, whom they define as Chinese and immigrant, being admitted for treatment of gestational diabetes. While the commitment of the Prairie Hospital to multicultural health care is strong, the medical staff at the OutPatient Diabetes Centre has identified gaps in social and cultural information available on Chinese immigrant women in this locale. Therefore, they lack the means to support these women and design programs to prevent future occurrences. The objective of this research project is to apply the techniques of clinical anthropology, as developed by Arthur Kleinman (1980), to elicit explanatory models of their illness from local women in order to understand the unique social, economical and cultural determinants of health among this ethnic and immigrant group. Documenting the explanatory models of Chinese immigrant women will provide an emic perspective concerning the experience of gestational diabetes. In addition, this ethnographic study will contribute an understanding of the etic perspective regarding the relationship between culture, immigrant status, and diabetes. This information will assist medical practitioners at the Prairie Hospital in negotiating the management of gestational diabetes among this ethnic immigrant group.

The proposed study will provide ethnographic data concerning the experiences of immigrant Chinese women by addressing the following questions (see attached guiding interview questions):

- What are these women's perceptions surrounding the risk factors for developing gestational diabetes?
- What do they perceive as constituting a normal pregnancy and how do they manage a typical pregnancy?

<sup>&</sup>lt;sup>26</sup> In my original ethics proposal, the name of the hospital was included. Here it has been changed to protect the anonymity of participants. In addition, pseudonyms have been used for all proper names excluding those of my supervisors and myself.

- What are their opinions concerning how gestational diabetes is perceived and treated in their origin locales? How do they perceive the various cultural perceptions surrounding the state of pregnancy and difficulties that may arise during pregnancy? Do they observe differences between how gestational diabetes is perceived in their home locales in comparison to Edmonton?
- What do these women believe are the underlying factors (social, economical, and cultural), which may affect their health in regards to the development and management of gestational diabetes as well as their ability to access health care?

#### Benefits of the Proposed Research

#### 1. Benefits to Chinese immigrant women:

- Provides them the opportunity to discuss their fears and hopes about their pregnancy in a context, which is less power-laden than that characterized by the clinical setting.
- Eliciting women's explanatory model for their gestational diabetes may enhance teaching and eventual acceptance of medical recommendations.
- Potential to improve their health care and that of other women of the immigrant and Chinese community.
- Introduces their cultural concepts and their voices into the corpus of local health services information.
- Expanded communication has the potential to enhance the entire perinatal experience.

#### 2. Benefits for the Child (unborn/infant):

- Reduced potential for peri-natal risks (i.e. macrosomia, birth trauma, and neonatal hypoglycemia) and for later problems (i.e. increased risk for obesity and diabetes, prolonged newborn jaundice, low blood calcium, and respiratory distress syndrome) if mothers in the study follow medical recommendations more closely during pregnancy.
- Potential to normalize pediatric services from at-risk child to healthy baby care.

#### 3. Benefits to the Staff at the Prairie Hospital:

- Facilitates clinic staff in their roles as health care providers.
- Supports the commitment of hospital staff to incorporate cultural identity, values, and practices in health services by strengthening cultural responsiveness.
- Promotes dialogue between and among patients and health care providers.

#### 4. Benefits to Academia:

- Documenting relationship of culture and health, in a local and Canadianspecific context.
- Augment and expand anthropological research demonstrating the potential impact of immigrant status to the health of newcomers.
- Demonstrate methodology and benefits of clinically applied anthropology to patients and medical practitioners.
- Provide baseline ethnographic data about various Chinese immigrant women in Edmonton

#### Methodology of Proposed Research

In order to answer the research questions outlined under the 'Purpose of the Research', ethnographic fieldwork will be conducted at the Prairie Hospital in Edmonton, Alberta. This fieldwork will include three different components: retrospective chart review, observation in the clinic, and multiple, open-ended triangulated (follow-up) interviews.

- 1. Chart review: A review of each patient's medical charts will provide baseline information on the informant's medical history, documentation of conception date, first appointment in regards to pregnancy, as well as documentation of interactions with the medical staff at the Prairie Hospital in relation to gestational diabetes. Language spoken and immigrant status may also be identified from the chart. This information is critical for the analysis of when and how Chinese immigrant women seek health care, especially in relation to pregnancy. Chart reviews may only be conducted once the researcher (Lisa Wozniak, MA candidate) receives consent from individual participants and the clinical staff.
- 2. Observation: With the consent of informants, as well as the clinic personnel and with due regard to confidentiality, the researcher (Lisa Wozniak, MA candidate) may attend clinic sessions. The most appropriate means to facilitate consent in regards to these observations would be to ask the women who have agreed to be interviewed if I could also sit in on their clinic sessions. In the interview setting, the women will have already been informed about the study, provided consent for the interview, and will understand the issues surrounding confidentiality and their right to withdraw from the study. All participants will be informed of their right to decline the researcher's participation in this aspect of their clinical care. In addition, it will be made explicit that informants can withdraw their consent allowing the researcher to attend their clinical sessions at any time during the study.
- 3. Interviews: The researcher (Lisa Wozniak, MA candidate) will conduct one on one, open-ended, confidential interviews with the informants. In order to avoid pressuring women into participating in this study, posters and brochures with information regarding the research project will be available at the OutPatient Diabetes Centre (see attached poster and information letter). Both the posters and informational handouts will have the researcher's contact information. Therefore, women can make it know to the researcher their interest in learning more about the

research project or participating in the study on their own accord. In addition, a neutral person in the clinical setting, the translator, may recruit informants by acting as a cultural broker in explaining the research project to potential participants.

Regarding the setting of the interviews, each participant will choose a location based on their comfort level. Potential interview locations include the hospital, the women's homes, or other quiet spaces (i.e. coffee shop). The interviews will be staggered and each will take approximately 20 minutes. However, women who wish to talk longer or who need more time because of language issues will be accommodated. An estimated two interviews will be requested of each participant. As well, and according to their willingness, the researcher (Lisa Wozniak, MA candidate) may conduct interviews with clinic staff. All interviewees will be asked to sign an Interview Consent form (see attached interview consent form) or consent will be recorded on audiocassettes if any informant is uncomfortable signing a document. Regardless of whether the researcher (Lisa Wozniak, MA Candidate) requests interviews with clinic staff, all members of the OutPatient Diabetes Centre will be provided with an information letter explaining the purpose and methodology of this research project (see attached information letter for clinic staff). This procedure will be followed to ensure that clinic personnel are aware of the research being conducted at the OutPatient Diabetes Centre.

The emphasis of interviews will be to allow the informants to freely discuss their perceptions of their condition and their concerns regarding their health care (see attached guiding interview questions). When needed, a language interpreter will be provided and compensated for by the Multicultural Program at the Prairie Hospital (contact person is Ann Webb). Interview subjects will focus primarily on the women's perception of their condition, concerns about health care and services, duration of time in Canada, and socio-economic status in relation to their health seeking strategies. With participants' consent, each interview will be documented on audiotapes.

4. **Data Analysis:** Data will be catalogued and analyzed thematically and correlated with academic and clinical literature on Chinese and immigrant health. A report from the results of the research will be presented to the staff of the OutPatient Diabetes Centre and Multicultural Program at the Prairie Hospital.

#### Problematic Nature of Defining the Study Group

It is necessary to address the problematic definition of 'Chinese' and 'immigrant' women involved in this research project. Several scholars reject the notion of labelling people based on ancestry and any attempt to study people based on this demarcation. Therefore, the use of the term 'community' may better reflect the characteristics of this group. Traditionally, the concept of community represents features such as relative homogeneity, stability, and a sense of belonging with the group maintaining well-defined geographic, political and socio-economic boundaries. However, the term 'community' has become increasingly ambiguous in regards to defining a group of people. In this research project, for instance, the process of immigration itself makes it difficult to provide specific criterion for defining the

research group. Women in this study may come from various socio-economic positions, may have lived in diverse regions of China or Southeast Asia, and may speak different dialectics. However, for the purposes of this research, these women share common experiences in engaging the biomedical institution as outsiders. Indeed, the terms and categorizations are problematic but do not negate the necessity to understand the experiences of these women in relation to their health.

### SECTION B: Incorporation of the Tri-Council recommendations for the standard of 'good practice' in research

This research project will be conducted in accordance with the research ethics guidelines set by the Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans and the University of Alberta Standards for the Protection of Human Research Participants (1999 GFC Policy Manual, Section 66). All research activities will adhere to and respect the eight Guiding Ethical Principles, which are outlined in detail below.

#### Principle 1: Respect for Human Dignity

The following principle dictates that the researcher (Lisa Wozniak, MA candidate) must "protect the multiple and interdependent interests of the person – from bodily to psychological to cultural integrity – as they may be affected by the research". This research project will have no repercussions for the bodily integrity of the informants as their status as participants will remain undisclosed to the health practitioners at the hospital. In regards to psychological and cultural integrity, all participants will be informed of their right to discontinue participation in this research project if at any time they perceive a negative impact on their mental health or cultural values. Adhering to the principle of free and informed consent, all participants will be treated with respect and dignity.

#### **Principle 2: Respect for Free and Informed Consent**

Potential research participants will be initially informed of this study through the use of informational posters placed on the walls of the OutPatient Diabetes Centre, which will briefly outline the purpose of this research project (see attached poster). Posters will be translated into different Chinese dialects. The posters will direct potential informants to information letters available in the waiting room of the OutPatient Diabetes Centre (see attached information letter). As with the posters, the information letters will be translated. In addition to the written information available to women outlining this research project, a neutral person in the clinical setting may inform potential informants of the study. The only appropriate person to inform women of this research project is the translator. The translator is more likely to be viewed as a member of the community and, as such, may act as a cultural broker for these women. These procedures will be followed in order to avoid making women feel pressured into participating in this research project.

The Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans insists that researchers respect the "exercise of individual consent". Therefore, each participant in this research project will be explicitly informed of my status as a researcher, the purpose and methodology of the study, as well as my intention to publish research results in academic forums. In addition, all participants will be advised that they may withdraw from the project at any time during the study, including during the interviewing process. Also, informants will be notified that their participatory status in the research project will not be communicated to any health practitioners. After being informed of the research objectives and prior to conducting interviews, the participants will be asked to sign an Interview Consent form (see attached interview consent form), which I will review with each individual with the assistance of an interpreter, if needed, that outlines the above information. However, if any individual is uncomfortable signing a consent form, their oral consent will be recorded on audiocassettes.

#### Principle 3: Respect for Vulnerable Persons

The guidelines provided by the University of Alberta Standards for the Protection of Human Research Participants outlines that vulnerable persons include children and those who are institutionalized who lack competence or decision-making capacities. In addition, the status of participants in this research project as 'immigrant' could be added to the U of A Standards for the Protection of Human Research Participants' definition of vulnerable persons. It may be argued that vulnerable persons, such as immigrants, may agree to requests made by authority figures to be respectful. As such, the researcher (Lisa Wozniak, MA candidate) must employ special procedures to ensure their interests are protected.

In regards to their status as immigrants, the use of informational posters and brochures and/or initial contact by a neutral person in the clinical setting, such as the translator, will alleviate feelings of pressure or obligation for the women to participate in this research project. At this point, women who are interested in participating or want additional information will be given the researcher's (Lisa Wozniak, MA candidate) contact information or can provide the translator with their contact information. In addition to preventing the coercion of vulnerable persons to participate in this research project, issues regarding potential language barriers in relation to informed consent must be addressed. A translator will be provided for all non-English speaking participants or those who prefer to use their first language. Once potential informants have contacted the researcher (Lisa Wozniak, MA candidate), each informant will be asked to sign a consent form or have their oral consent recorded upon being informed of the objectives, methods, and possible publication of the research project and reviewing the consent form in the language of their choice. In addition, each informant will be explicitly informed of her right to discontinue participation in this research project at any time with no explanation necessary.

## Principle 4: Respect for Privacy and Confidentiality

This principle is in place to "protect mental or psychological integrity and where appropriate, to preserve anonymity". Therefore, participants will be explicitly informed of the nature of this research project and their rights as participants, in writing, and/or verbally with an interpreter if necessary. All informants will be made aware of their right to anonymity. To ensure this, the researcher (Lisa Wozniak, MA candidate) will employ a pseudonym for each informant. Each pseudonym will be coded with a number. In a separate document, each number will be correlated with the identity of each informant. This information will remain in a secure and locked office. Therefore, the participants will be guaranteed that their anonymity will not be compromised.

In addition, participants' privacy will not be invaded during the interview process. If the participant seems or expresses reluctance to continue, the interview will be terminated immediately, and/or rescheduled for another time. To ensure that privacy and confidentiality is maintained, any informant who discontinues participation in this research project will be given all information based on their testimony, which has been recorded by the researcher (Lisa Wozniak, MA candidate) in the form of notes and/or audiotapes.

## Principle 5: Respect for Justice and Inclusiveness

Under this principle, the Tri-Council Policy Statement affirms that "no segment of the population should be unfairly burdened with the harms of research" and to not "discriminate against individuals or groups who may benefit from advances in research". In accordance with this principle, my research and the data collected will be used solely for academic purposes. My conclusions will become part of the public record through academic publication for discussion and, as such, not the sole property of the Prairie Hospital. Therefore, no specific group or individuals will be burdened or have beneficial rights to my academic research.

Principle 6: Balancing Harms and Benefits and

Principle 7: Minimizing Harm and Principle 8: Maximizing Benefit

The benefits of the research project are outlined in Section A of this ethics proposal. I anticipate no adverse effects to be encountered by the research informants, which would be any worse than their current clinical experience, and the potential for benefit outweighs the potential risks. If any, potential risks could be of a psychological nature, such as concern about invasion of privacy or embarrassment. However, the research design follows the "Tri-Council Policy Statement - Ethical Conduct for Research Involving Humans". These guidelines ensure the cultural, physical, and psychological integrity of all participants. All research participants will be explicitly informed in writing and/or verbally, with an interpreter if necessary, of the nature of this research, their right to free and informed consent, their right to withdraw from the study at anytime, and that their privacy will be protected.

I am cognizant of the critiques made to whit: that clinical anthropology may assist physicians in promoting patient compliance while still ignoring the social, economical, and cultural contexts of ethnic groups (Young 1982 and Taussig 1980). For example, Young (1980) suggests that Kleinman's (1980) earlier approach to clinical anthropology neglects the processes through which dominant ideologies of society are reproduced in the medical sphere. From Young's point of view, medical practices are "simultaneously ideological practices when they justify (a) the social arrangements through which disease, healing, and curing are distributed in society...and (b) the social consequences of sickness (e.g. the patient's liability for disease he contracts in the workplace)" (1982: 271). By downplaying the significance of dominant ideologies, it has been suggested that Kleinman's (1980) clinical anthropology framework may act to reproduce and replicate the power structures that exist in the medical setting (Young Leslie 2001). Critics argue that the result of neglecting the dominant ideological framework replicated in biomedicine can promote patient compliance while continuing to discount the social, economical, and cultural context of ethnic groups.

The commitment of the Prairie Hospital to Multiculturalism and the acknowledgment that cultural identity can enhance healing and well being assures this researcher that the findings of this project will not be used to replicate any unequal balances of power between medical professionals and patients. Based on the environment produced by the Prairie Hospital to respect cultural integrity, I am confident that the findings of this research project will be used to enhance communication and understanding between medical professionals and patients in the management of gestational diabetes among Asian immigrants.

I have read, understood, and will adhere to the guidelines of the Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans, and the "University of Alberta Standards for the Protection of Human Research Participants" (GFC Policy Manual, Section 66) and agree to abide by these standards in conducting research.

## UNIVERSITY OF ALBERTA CERTIFICATION OF ETHICAL ACCEPTABILITY

#### DEPARTMENT OF ANTHROPOLOGY HUMAN RESEARCH ETHICS ADVISORY GROUP

APPLICANT'S NAME: Lisa WOZNIAK

APPLICANT'S DEPARTMENT: Anthropology

**APPLICATION TITLE:** 

\_ .<u>a</u>

"The Socioeconomics & Cultural Contexts of Chinese Immigrant

Women with Gestational Diabetes: A Case Study"

DATE SUBMITTED: 24 April 2002

The application noted above was reviewed by the Department of Anthropology Ethics Advisory Group. The Advisory Group was constituted and the decision was rendered as specified in the "Tri-Council Policy Statement - Ethical Conduct for Research Involving Humans," and the "University of Alberta Standards for the Protection of Human Research Participants", 1999 GFC Policy Manual, Section 66. The committee reviewers for this application are listed below.

This is to certify that the project and/or procedures outlined in the application were found to be acceptable on ethical grounds and to be generally in accord with policy guidelines as laid down by this University for such research involving human participants.

Dr. Cliff Hickey, Professor

May 2001 Date Approved

Department of Anthropology Ethics Advisory Group

Statutory Member of Faculty of Arts Research Ethics Board

Reviewers for this application: Michelle Daveluy

Raymond LeBlanc

Pamela Willoughby

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## Appendix 3

#### **Informational Poster**

**Project Title:** The Cultural Contexts of Chinese Immigrant Women with Gestational Diabetes: A Case Study at the Prairie Hospital in Edmonton, Alberta<sup>27</sup>

## Principal Investigator:

Lisa Wozniak (MA candidate) 13-15 HM Tory Building Department of Anthropology University of Alberta Phone: (780) 492-9879 E-mail: lwozniak@ualberta.ca

## **Secondary Contact:**

Dr. Rod Wilson (Supervisor) 13-26 HM Tory Building Department of Anthropology University of Alberta Phone: (780) 492-0137 E-mail: rodwil@oanet.com

## Purpose of this Study:

Some women experience symptoms of diabetes during their pregnancy, which usually goes away after the baby is delivered. As you know, this is called gestational diabetes. Gestational diabetes occurs in one out of every 20 pregnancies in the general Canadian population. However, little information is available to Canadian health professionals that can help them understand how Chinese immigrant women generally think about and manage gestational diabetes. The purpose of this research project is to talk with Chinese immigrant women to learn more about how you deal with your gestational diabetes.

Mostly, I want to hear what <u>you</u> have to say about this pregnancy, any previous pregnancies, and your gestational diabetes. You will decide where you would like the interview to take place. This can either be at the hospital, your home, or another quiet place. In general, the interviews will last around 20 minutes and I would like to talk to you at least twice. However, if you want to talk longer or if we need a translator to help you participate, that is fine. I will ask for some basic information such as your age, job, home country, and how long you have been living in Canada. If you have been pregnant before, I will ask certain questions about those pregnancies.

In addition to the interviews, I will ask your permission to look at your hospital chart. The information I wish to get from the charts includes basic clinical information such as how many weeks pregnant you were when gestational diabetes was diagnosed, how the medical staff diagnosed it, and what types of treatment or monitoring were recommended. However, you have the right to keep your hospital charts private and can still participate in this study.

<sup>&</sup>lt;sup>27</sup> In the original poster, the name of the hospital was included. It has been changed here to maintain participant anonymity.

Finally, I would like to sit in on part of your session with the physician, if you agree. Observing the doctor-patient interaction will be helpful for understanding how health messages are best transmitted. However, you need not remove yourself from the study if you want your time with the doctor private and you can decide later in the study if you want to permit me to participate.

For more details regarding this study and how to contact the researcher, please take an information letter available in the waiting room of the Diabetes Outpatient Clinic. You are under NO obligation to participate in this study even if you take an information letter.

#### **Informational Poster in Chinese Characters**

## 信息通報

項目名稱: 患有孕期糖尿病的中國移民婦女的社會經濟及文化背景: 阿伯達省愛民頓市皇家亞歷山大醫院病例研究。

# 主調查員:

Lisa Wozniak (文學碩士候選人) 13-15 HM Tory 大樓 人類學系 阿伯達大學

電話: (780)492-9879 電郵: lwozniak@ualberta.ca

## 其它聯係人:

Rod Wilson 醫生(導師) 13-26 HM Tory 大樓 人類學系 阿伯達大學

電話: (780)492-0137 電郵: rodwil@oanet.com

## 研究目的:

懷孕期間,有部份婦女患有糖尿病症狀,這些症狀通常在孩子出生後會消失。 這就是通常稱的孕期糖尿病。在加拿大人口中,大約每二十個孕婦中就有一人患有孕期糖尿病。然而,對于中國移民婦女通常是怎樣看待和處理孕期糖尿病, 加拿大醫療人員由于缺乏信息而在這方面缺乏理解。該研究項目的目的是通過和中國婦女的交談以了解您是怎樣對待孕期糖尿病的。

我主要是想聽您講述這次和以前懷孕的經歷以及您的孕期糖尿病。您決定在哪裡見面:在醫院,您家裡或者是其它安靜的地方。總之,面訪將持續的貳拾分鐘,我至少要和您見兩次面。但是,如果您願意談長一點時間或者是需要翻譯在場都可以。我會問一些基本信息如您的年齡、工作、出生國以及在加拿大住了多久。如果您以前懷過孕,我會詢問關於您以前懷孕的情況。

除了見面外,我需要您的同意去看您的醫院病歷。從醫院病歷中,我希望能獲得的信息包括基本的臨床信息如在懷孕幾星期後醫生診斷出您患有孕期糖尿病、醫生是怎樣診斷出來的,又作出了什麼治療和監測。 然而,即便您不顧公開醫院病歷,您仍可以參加這項研究。

最後,如果您同意,在您和醫生見面時,我會在場聽一段時間。通過觀察醫生和病人的交流,會有助于我理解怎樣最好的交流健康信息。然而,如果您只想和醫生單獨見面,您仍可以參加這個研究項目,您可以以後在決定是否允許我在場。

要想了解該研究更多的細節和怎樣聯絡研究人員,請到糖尿病門診中心的候客室提取信息書。即使拿到信息書後,您没有任何義務參加這項研究。

## Informational Letter/Brochure

**Project Title:** The Cultural Contexts of Chinese Immigrant Women with Gestational Diabetes: A Case Study at the Prairie Hospital in Edmonton, Alberta<sup>28</sup>

## Principal Investigator:

Lisa Wozniak (MA candidate) 13-15 HM Tory Building Department of Anthropology University of Alberta Phone: (780) 492-4277 E-mail: lwozniak@ualberta.ca

## **Secondary Contact:**

Dr. Rod Wilson (Supervisor) 13-26 HM Tory Building Department of Anthropology University of Alberta Phone: (780) 492-0137 E-mail: rodwil@oanet.com

## Purpose of this Study:

Some women experience symptoms of diabetes during their pregnancy, which usually goes away after the baby is delivered. As you know, this is called gestational diabetes. Gestational diabetes occurs in one out of every 20 pregnancies in the general Canadian population. However, little information is available to Canadian health professionals, which can help them understand how Asian women generally think about and manage gestational diabetes. The purpose of this research project is to talk with Asian immigrant women to learn more about how you deal with your gestational diabetes.

#### Benefits of this study:

While we believe that talking about your pregnancy and your gestational diabetes will be a comfortable and positive experience, we cannot promise you any direct or immediate benefits for your participation in this study. However, our goal is to use the information you provide to improve the future options for pregnant women, like you, and their unborn infants. This project will help the staff of the Prairie Hospital to provide even better care for women with gestational diabetes from the Asian community in Edmonton.

## Possible risks involved in this study:

There will be **no physical risks** for you or your baby, but it may be uncomfortable speaking to a researcher about your pregnancy or pregnancies, your status as an immigrant, and your experiences visiting the hospital. However, if you are ever uncomfortable, you have the right to not answer any question and to discontinue participating in this project at any time, even during the interview.

<sup>&</sup>lt;sup>28</sup> In the original poster, the hospital name was included. It has been changed here to protect participant anonymity.

## The Rights of Participants:

Your health care will not be affected whether or not you decide to be a part of this study.

- Your real name will **never** be used in this study. The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (i.e. locked filing cabinet). Your name or any other identifying information will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results
- You have the right to privacy and confidentiality. All information will be held confidential (or private) except when professional codes of ethics or legislation (or the law) require reporting. This is because all researchers must report abuse under Acts such as the Child Welfare Act and Protection for Persons in Care Act.
- You have the right to refuse to answer ANY question
- You have the freedom to withdraw from this study at ANY time with no explanation needed
- Your have the right to ask the researcher any questions you may have
- The information gathered for this study might be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically

## What will happen during this study?

Mostly, I want to hear what you have to say about this pregnancy, any previous pregnancies, and your gestational diabetes. You will decide where you would like the interview to take place whether it be at the hospital, your home, or some other quiet place. In general, the interviews will last around 20 minutes and I would like to talk to you at least twice. However, if you want to talk longer or if we need a translator to help you participate, that is fine. I will ask for some basic information such as your age, job, home country, and how long you have been living in Canada. If you have been pregnant before, I will ask certain questions about those pregnancies.

In addition to the interviews, I will ask your permission to look at your hospital chart. The information I wish to get from the charts includes basic clinical information such as how many weeks pregnant you were when gestational diabetes was diagnosed, how the medical staff diagnosed it, and what types of treatment or monitoring were recommended. However, you have the right to keep your hospital charts private and can still participate in this study.

Finally, I would like to sit in on part of your session with the physician, if you agree. Observing the doctor-patient interaction will be helpful for understanding how health messages are best transmitted. However, you need not remove yourself from the study if you want your time with the doctor private and you can decide later in the study if you want to permit me to participate.

#### Who will have access to this research?

Clinical staff at the Prairie Hospital will receive a report outlining the results of this project. The same report will be made available on request to local community organizations such as Catholic Social Services or the Edmonton Mennonite Centre for Newcomers. In addition, a thesis will be produced which will be read by the committee members and which will be available on request to the academic community. Finally, the results could be published for scholarly reasons.

If you are interested in participating in this project, or if you would like more information, please contact the principal investigator, Lisa Wozniak.

## Informational Letter in Chinese Characters

## 信息書

項目名稱:患有孕期糖尿病的中國移民婦女的社會經濟及文化背景:阿伯達省愛民頓 市皇家亞歷山大醫院病例研究。

# 主調查員:

Lisa Wozniak (文學碩士候選人) 13-15 HM Tory 大樓 人類學系 阿伯達大學

電話 (780)492-9879 郵: lwozniak@ualberta.ca

# 其它聯係人:

Rod Wilson 醫生(導師) 13-26 HM Tory 大樓 .類學系

括: (780)492-0137 rodwil@oanet.com

## 研究目的:

懷孕期間,有部份婦女患有糖尿病症狀,這些症狀通常在孩子出生後會消失。 這就是通常稱的孕期糖尿病。在加拿大人口中,大約每二十個孕婦中就有一人患有孕期糖尿病。然而,對于中國移民婦女通常是怎樣看待和處理孕期糖尿病, 加拿大醫療人員由于缺乏信息而在這方面缺乏理解。該研究項目的目的是通過和中國婦女的交談以了解您是怎樣對待孕期糖尿病的。

# 研究補貼:

雖然我們相信談論您的懷孕和孕期糖尿病是個輕鬆又積極的經歷,但是我們無法保障您參與這項研究會得到任何直接或間接的補貼。然而,我們的目的是通過您提供的信息來開闊有和您經歷相同的孕婦和未世嬰兒的未來的選擇。該項目會有助于皇家亞歷山大醫院工作人員給愛民頓華人區患孕期糖尿病的婦女提供更好的服務。

# 參預該研究可能的風險:

對您和嬰兒無任何身體上的危險。也許和研究人員談懷孕和移民身份及去醫院的經歷會 讓您感到不舒服,然而,如果您有任何不適,在任何時候,即便是在會面中,您也有權 拒絕回答問題,停止參與該項目。

# 參預人權力:

不管您是否參預該研究的一部份,您的健康福利不會受到任何影響。

- 該研究不使用您的真實姓名。您提供的信息在研究結束後會被保留至少五年。該信息會被保留在安全區域(比如,上鎖的文件箱)。您的名字和任何可以證實您身份的信息不會和您提供的信息存在一起。您的名字不會出現在任何現場講解或公佈的研究結果中。您有隱私權。所有信息將會被作爲機密或保密文件進行處理,除非是職業道德標準或行政或法律要求匯報。因為一些法案如兒童福利法和受保護人法要求所有研究人員心循歷報具處行實
- 有研究人員必須匯報暴虐行為。
  您有權拒絕回答任何一個問題。

- -- 您有權不作任何解釋而在任何時候取消參加該研究的自由。 您有權問研究人員任何問題。 -- 將來寫了幫助解答其它研究問題,該研究提供的信息會再次被閱覽。在這種 情況下,道德理事會將檢查該研究以保障提供的信息得到道義上合理的使用。 -- 在研究中將出現什麼事?

我主要是想聽您講述這次和以前懷孕的經歷以及您的孕期糖尿病。您決定在哪裡見面:在醫院,您家裡或者是其它安靜的地方。總之,面訪將持續約貳拾分鐘,我至少要和你見兩次面。但是,如果您願意談長一點時間或者是需要翻譯在場都可以。我會問一些基本信息如您的年齡、工作、出生國以及在加拿大住了多久。如果您以前懷過孕,我會詢問關於以前懷孕的情況。

除了見面外,我需要您的同意去看您的醫院病歷。從醫院病歷中,我希望能獲得的信息包括基本的臨床信息如在懷孕幾星期後醫生診斷出您患有孕期糖尿病、醫生是怎樣診斷出來的,作出了什麼治療和監測。然而,即便您不顧公開醫院病歷,您仍可以參加這 項研究。

最後,如果您同意,在您和醫生見面時,我會在場聽一段時間。通過觀察醫生和病人的交流,會有助于我理解怎樣最好的交流健康信息。然而,如果您只想和醫生單獨見面, 您仍可以參加這個研究項目,您可以以後再決定是否允許我在場。

## Guiding Interview Questions for Asian Women

## **Basic/Demographic Information:**

- 1. How old are you?
- 2. What is your home country and in which region did you live?
- 3. When did you come to Canada?
- 4. How did you enter Canada?
- 5. Did you live in any other countries before coming to Canada?
- 6. How is your family composed and where do they live?
- 7. How comfortable are you speaking English in your everyday life?
- 8. What is your formal educational background?
- 9. Are you employed?
- 10. What other kinds of work are you responsible for? (i.e. household work, childcare, volunteering, assisting other family members new to Canada)

## **Explanations Concerning Gestational Diabetes:**

- 1. What do you call your problem/condition? What name does it have?
- 2. What do you think has caused your problem?
- 3. Why do you think it started when it did?
- 4. What does your sickness do to you? How does it work [in your body]?
- 5. How severe is it? Will it have a short or long course?
- 6. What do you fear most about your sickness?
- 7. What are the chief problems your sickness has caused you?
- 8. What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?

# Perceptions Surrounding Pregnancy:

- 1. Describe what a normal pregnancy is to you?
- 2. In your point of view, what are you suppose to do when you are pregnant?
- 3. What aren't you suppose to do when pregnant?
- 4. How did you come to use the Diabetes Outpatient Clinic at the Prairie Hospital? When did you first use the clinic's services/how far into your pregnancy?
- 5. Does any of the medical staff speak your language of choice?
- 6. If not, what do you do when you come to the clinic?
- 7. How do you feel about hospitals and the medical staff?
- 8. Do you understand everything that medical staff tells you?
- 9. If you don't understand, what do you do?
- 10. Do you use alternative medicines or treatments for gestational diabetes?
- 11. If so, what kinds/types?
- 12. Did you consult with any alternative health advisors before visiting a Western trained physician? Why?
- 13. What made you decide to see a Western trained physician?

# Guiding Interview Questions for Traditional Chinese Medical (TCM) Practitioner

#### **Background Information**

- 1. Tell me about your educational and medical training in both China and Canada.
- 2. How long have you been practicing in Canada?
- 3. Do you see pregnant women?

## TCM Conceptualizations of Pregnancy and Gestational Diabetes

- 1. What can you tell me about pregnancy, from a TCM perspective?
- 2. How is it understood?
- 3. How is it treated (managed? ignored?)
- 4. What about the woman herself while pregnant?
- 5. What do you advise she should do?
- 6. What do you advise a woman should not do while pregnant?
- 7. What problems do TCM doctors watch for with pregnant women?
- 8. Biomedical doctors talk about gestational diabetes and glucose intolerance. Are these recognized in TCM?
- 9. How is gestational diabetes described and explained within this context?
- 10. What do you tell women about gestational diabetes or glucose intolerance?
- 11. From the perspective of TCM, how is gestational diabetes diagnosed?
- 12. Who gets screened for gestational diabetes (and why)?
- 13. How is it tested for?
- 14. What are the diagnostic criteria used to label a woman as a gestational diabetic?
- 15. What kind of treatment exists in TCM for gestational diabetes?

## Specific Practices related to Pregnancy and TCM

- 1. According to TCM, what must a woman do to ensure a healthy and successful pregnancy?
- 2. Can you tell me about dietary practices related to pregnancy?
- 3. Can you speak to the concept of Yin and Yang in relation to pregnancy?

## **Guiding Interview Questions for Clinicians**

#### **General Information**

- 1. What is your occupational title?
- 2. Walk me through your typical workday starting from when you clock in until the end of your shift.
- 3. What is the most rewarding aspect for you job here at the clinic?
- 4. What would you say is the least rewarding aspect/or disadvantage of working at the clinic?

# Providing care to Chinese-speaking immigrants with gestational diabetes (GD)

- 1. How does working with a translator change your typical appointment?
- 2. In your opinion, what is the most essential information you must transmit to every patient you see in regards to GD?
- 3. How do you know that a Chinese-speaking patient does or does not understand something you have told them?

## Experiences with Chinese-speaking Patients with GD

- 1. What do you consider to be the most challenging/frustrating aspect in providing care to Chinese-speaking clients?
- 2. What is the most rewarding aspect?
- 3. What kinds of questions do Chinese-speaking women ask you about gestational diabetes?
- 4. Do you think that Chinese-speaking immigrant women are at a disadvantage receiving healthcare in Canada for gestational diabetes as opposed to in their home country?
- 5. In your experience, do Chinese-speaking immigrant women with gestational diabetes adhere to your recommendations for its management and treatment?
- 6. Please tell me about an experience you have had when a Chinese-speaking woman was satisfied with her care. And when a woman was not happy?
- 7. What would make your job as a healthcare provider easier when dealing with this immigrant group?

#### **Explanatory Models**

- 1. How do you think Chinese-speaking immigrant women would label their condition? What do they understand about GD and its impact on their health and their child's health?
- 2. What would they say caused them to develop GD during their pregnancies?
- 3. How would Chinese-speaking women explain a) how GD works in their bodies' and b) what it does to their bodies'?
- 4. How severe do Chinese-speaking women believe GD is to their health and their babies' health?
- 5. Do they believe it will have a long or short course?
- 6. What are the major problems that living with GD have caused these women?

7. What do Chinese-speaking immigrant women tell you they fear the most about GD?

# **Understanding of Traditional Chinese Medical Notions Surrounding Pregnancy**

- 1. What do you know about the concept of Yin and Yang as it relates to Traditional Chinese Medicine?
- 2. What do you know about the predominant medical systems in China?
- 3. What do you know about the recommended Southeast Asian diet in relation to GD?

## Informational Letter for Clinicians and Traditional Chinese Medicine Practitioner

**Project Title:** The Cultural Contexts of Asian Immigrant Women with Gestational Diabetes: A Case Study at the Prairie Hospital in Edmonton, Alberta<sup>29</sup>.

## Principal Investigator:

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#### **Secondary Contact**

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## Purpose of this study:

Health practitioners at the Prairie Hospital report a high percentage of women, who they define as Asian and immigrant, being admitted for treatment of gestational diabetes. While the commitment of the Prairie Hospital to multicultural health care is strong, the medical staff at the Diabetes Outpatient Clinic have identified gaps in social and cultural information available on Asian immigrant women in this locale. Therefore, they lack the means to support these women and design programs to prevent future occurrences. The purpose of this research project is to talk with Asian immigrant women to learn more about how they understand their gestational diabetes and its management. The objective of this research project is to apply the techniques of clinical anthropology, as developed by Kleinman (1980), to elicit information necessary for understanding the unique social, economical, and cultural determinants of health among this ethnic and immigrant group in Edmonton. This information will assist medical practitioners at the Prairie Hospital in negotiating the management of gestational diabetes among this ethnic group.

### Benefits of this study:

#### 1. Benefits to Asian immigrant women:

• We believe that this project provides Asian immigrant women with the opportunity to discuss their fears and hopes about their pregnancy in a context which is less power-laden than that characterized by the clinical setting. However, we cannot promise these women any direct or immediate benefits for their participation in this study. However, our goal is to use the information they provide to improve the future options for pregnant women and their unborn infants.

## 2. Benefits for the Child (unborn/infant):

<sup>&</sup>lt;sup>29</sup> In the original informational letter, the hospital name was included. Here it has been changed to maintain participant anonymity.

• Potential to normalize pediatric services from at-risk child to healthy baby care.

## 3. Benefits to the Staff at the Prairie Hospital:

- Facilitates clinic staff in their roles as health care providers.
- Supports the commitment of hospital staff to incorporate cultural identity, values, and practices in health services by strengthening cultural responsiveness
- Promotes dialogue between and among patients and health care providers.

#### 4. Benefits to Academia:

- Documenting relationship of culture and health, in a local and Canadianspecific context.
- Augment and expand anthropological research demonstrating the potential impact of immigrant status to the health of newcomers.
- Demonstrate methodology and benefits of clinically applied anthropology to patients and medical practitioners.
- Provide baseline ethnographic data about various Asian immigrant women in Edmonton.

## Possible risks involved in this study:

I anticipate no adverse effects to be encountered by the research informants, which would be any worse than their current clinical experience, and the potential for benefit outweighs the potential risks. If any, potential risks could be of a psychological nature, such as concern about invasion of privacy or embarrassment. However, the research design follows the "Tri-Council Policy Statement - Ethical Conduct for Research Involving Humans". These guidelines ensure the cultural, physical, and psychological integrity of all participants. All research participants will be explicitly informed in writing and verbally, with an interpreter if necessary, of the nature of this research, their right to free and informed consent, their right to withdraw from the study at anytime, and that their privacy will be protected.

#### The Rights of Participants:

All informants in this research project will be explicitly told of their rights as participants. These rights include:

- Your real name will **never** be used in this study. The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (i.e. locked filing cabinet). Your name or any other identifying information will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results
- You have the right to privacy and confidentiality. All information will be held confidential (or private) except when professional codes of ethics or legislation (or the law) require reporting. This is because all researchers must

- report abuse under Acts such as the Child Welfare Act and Protection for Persons in Care Act.
- You have the right to refuse to answer ANY question
- You have the freedom to withdraw from this study at ANY time with no explanation needed
- Your have the right to ask the researcher any questions you may have
- The information gathered for this study might be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

## Methodology of the study:

In order to understand the current cultural contexts of Asian immigrant women with gestational diabetes seeking treatment at the Prairie Hospital, ethnographic fieldwork will be conducted. This fieldwork will include three different components: retrospective chart review, observation in the clinic, and open-ended, multiply triangulated (follow-up) interviews.

- 1. Chart review: A review of each patient's medical charts will provide baseline information on the informant's medical history, documentation of conception date, first appointment in regards to pregnancy, as well as documentation of interactions with the medical staff at the Prairie Hospital in relation to gestational diabetes. Language spoken and immigrant status may also be identified from the chart. This information is critical for the analysis of when and how Asian immigrant women seek health care, especially in relation to pregnancy. Chart reviews may only be conducted once the researcher (Lisa Wozniak, MA candidate) receives consent from individual participants and the clinical staff.
- 2. Observation: With the consent of informants, as well as the clinic personnel and with due regard to confidentiality, the researcher (Lisa Wozniak, MA candidate) may attend clinic sessions. The most appropriate means to facilitate consent in regards to these observations would be to ask the women who have agreed to be interviewed if I could also sit in on their clinic sessions. In the interview setting, the women will have already been informed about the study, provided consent for the interview, and will understand the issues surrounding confidentiality and their right to withdraw from the study. All participants will be informed of their right to decline the researcher's participation in this aspect of their clinical care. In addition, it will be made explicit that informants can withdraw their consent allowing the researcher to attend their clinical sessions at any time during the study.
- 3. Interviews: The researcher (Lisa Wozniak, MA candidate) will conduct one on one, open-ended, confidential interviews with the informants. In order to avoid pressuring women into participating in this study, posters and brochures with information regarding the research project will be available at the Diabetes Outpatient Clinic (see attached poster and information letter). Both the posters and informational handouts will have the researcher's contact information. Therefore, women can make it known to the researcher their interest in learning more about the research project or participating in the study on their own accord. In addition, a

neutral person in the clinical setting, the translator, may recruit informants by acting as a cultural broker in explaining the research project to potential participants.

Regarding the setting of the interviews, each participant will choose a location based on their comfort level. Potential interview locations include the hospital, the women's homes, or other quiet spaces (i.e. coffee shop). The interviews will be staggered and each will take approximately 20 minutes. However, women who wish to talk longer or who need more time because of language issues will be accommodated. An estimated two interviews will be requested of each participant. As well, and according to their willingness, the researcher (Lisa Wozniak, MA candidate) may conduct interviews with clinic staff. All interviewees will be asked to sign an Interview Consent form (see attached interview consent form) or consent will be recorded on audiocassettes if any informant is uncomfortable signing a document. Regardless of whether the researcher (Lisa Wozniak, MA Candidate) requests interviews with clinic staff, all members of the Diabetes Outpatient Clinic will be provided with an information letter explaining the purpose and methodology of this research project (see attached information letter for clinic staff). This procedure will be followed to ensure that clinic personnel are aware of the research being conducted at the Diabetes Outpatient Clinic.

The emphasis of interviews will be to allow the informants to freely discuss their perceptions of their condition and their concerns regarding their health care (see attached guiding interview questions). When needed, a language interpreter will be provided and by the Multicultural Program at the Prairie Hospital (contact person is Ann Web<sup>30</sup>). Interview subjects will focus primarily on the women's perception of their condition, concerns about health care and services, duration of time in Canada, and socio-economic status in relation to their health seeking strategies. With participants' consent, each interview will be documented on digital voice recorder.

4. **Data Analysis:** Data will be catalogued and analyzed thematically and correlated with academic and clinical literature on Asian and immigrant health. A report from the results of the research will be presented to the staff of the Diabetes Outpatient Clinic and Multicultural Program at the Prairie Hospital.

#### Who will have access to this research?

Clinical staff at the Prairie Hospital will receive a report outlining the results of this project. The same report will be made available on request to local community organizations such as Catholic Social Services or the Edmonton Mennonite Centre for Newcomers. In addition, a thesis will be produced which will be read by the committee members and which will be available on request to the academic community. Finally, the results could be published for scholarly reasons.

Please feel free to contact me (Lisa Wozniak) if you have any questions or concerns regarding this research project.

<sup>&</sup>lt;sup>30</sup> The name, Ann Webb, is a pseudonym to maintain participant anonymity.

#### **Interview Consent Form**

Researcher/Interviewer: Lisa Wozniak

Department of Anthropology

University of Alberta

Edmonton, Alberta, Canada

T6G 2H4

As the interviewee, I have been fully informed of the following points before proceeding with the interview:

- 1. I have been asked to participate in a research study. My participation in this research is completely voluntary and I understand the intent and purpose of this research.
- 2. I have received and read a copy of the attached information sheet and understand the benefits and risks involved in taking part in this research study.
- 3. I understand that I am free to refuse to participate or withdraw from the study at any time. I understand that I do not need to give a reason for withdrawing from this research study and that this decision will not affect my care.
- 4. The issue of confidentiality has been explained to me and I understand that my identity will be kept confidential.
- 5. I know that I may refuse to answer any questions and that any information provided by me can be destroyed at any time upon my request.
- 6. I am aware that others will be reading the results of this research and that this research will eventually be published. In any publication, I will not be identified by name.

7.	Additional conditions for my participation in this research are noted here:		

8. I will receive a copy of this contract.

This study was explained to me by:
Date:
I agree to take part in this study:
Signature of Research Participant:
Printed Name:
I believe that the person signing this form understands what is involved in the stud- and voluntarily agrees to participate:
Researcher:
Printed Name:

#### **Consent Form in Chinese Characters**

# 接受訪問同意表

研究人/訪問人:

Lisa Wozniak 人類學系 阿伯達士學

加拿大阿伯達省愛民頓市

T6G 2H4

# 作為受訪人,我完全了解以下幾點:

- 1 我受邀参加該研究項目。我完全自願參與該研究,並明白該研究的目的和動機。
- 2 我拿到並閱讀了附件信息單的複印件,並了解參與該研究的補貼和風險。
- 3 我明白我有自由在任何時候拒絕參加或徹出該研究。我明白我不需要給任何理由撤出該研究項目,我的決定將不影響我的健康福利。
- 4 有人給我解釋了保密問題,並且我明白我的身份將得到機密保障。
- 5 我知道我可以拒絕回答任何問題,並且在我的要求下,我提供的任何信息可以被取消。
- 6 我知道有人將閱讀該研究的結果,該研究最終將得到發表。我的名字不會出現 在任何出版物中。

7	我參與該研究的其它條件包括:
8	我會收到該合同的複印件。
該研究	6由給我解釋。日期:
我同意	意参加該研究:
研究劉	9與人簽名:
研究爹	· 與人印刷體名:
我相信	官在該表上簽名的人明白參與該研究的事宜並自願參與研究。
研究人	·
研究人	、印刷體名: