Utilization Of Resources By Parents Of Children With Type 1 Diabetes Mellitus In The Prince George Area

Kornelia Friedrich

BScN., University of British Columbia, 1974

A Thesis Submitted In Partial Fulfillment Of

The Requirements For The Degree Of

Master Of Science

in

Community Health Science

The University Of Northern British Columbia

December 2007

Library and
Archives Canada

Published Heritage
Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et
Archives Canada

Direction du
Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 978-0-494-48807-2
Our file Notre référence
ISBN: 978-0-494-48807-2

NOTICE:
The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:
L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

Canada

Abstract

Diabetes is a complex disease affecting many people. Parents of children with type 1 diabetes face many difficulties requiring numerous resources to help them cope. It is the utilization of various resources that can help to slow or prevent the onset of complications. This descriptive study explores the resources used by parents and their satisfaction with these resources. A survey was sent to 60 parents of children with type 1 diabetes. Twenty-seven were completed and returned. The children were listed at the Prince George Diabetes Clinic (PGDC).

Overall, most parents indicated they used the PGDC and their pediatrician and are satisfied with these services, although wait times are a source of dissatisfaction. Family doctors and schools are not seen to possess the awareness or skills necessary to deal with situations that arise. Issues of need for financial help with diabetes supplies, and support for dealing with behaviour and emotional issues of children, particularly teenagers were commonly mentioned. Yet, expressed desires for support groups, youth camps or other services were mixed.

TABLE OF CONTENTS

LIST OF TABLES

ACKNOWLEDGEMENT

This project has been possible due to the involvement of a number of people. First I would like to thank the parents of children with type 1 diabetes that participated in the survey, without their involvement this thesis could not have been completed. The Prince George Regional Hospital Diabetes Clinic was very helpful in labelling and mailing my surveys. I would also like to thank my thesis committee: Dr. Willow Brown, Education, the External Examiner; Dr. Loraine Lavallee, Psychology; Dr. Sylvia Barton, formerly Nursing Program, UNBC, for their feedback and support. Also, I extend a special thank-you to Dr. Howard Brunt, former Provost of UNBC for his faith in me and his support. My dean at CNC, Patricia Covington, the CNC Faculty Association, and my family have all been strong supporters as I struggled through all the steps of completing this thesis. Most of all I thank Dr. Peter MacMillan, Community Health, my supervisor. His encouragement, support and assistance over the years, have made the completion of this thesis a reality.

CHAPTER ONE: RESEARCH PROBLEM AND LITERATURE REVIEW

Diabetes mellitus is a major health problem in Canada that affects over two million people (Canadian Diabetes Association, 2005, February 23). It is a disease whereby the body does not produce or respond effectively to the hormone, insulin. As the population ages, this number is expected to increase dramatically. In people who are diagnosed with diabetes, the pancreas, which produces insulin, functions inadequately. Systemic body impairment occurs when the pancreas stops producing insulin (type 1 or insulin-dependent diabetes) or produces insufficient insulin to meet the needs of the body (type 2 or non-insulin-dependent diabetes). A third type of diabetes, gestational diabetes, is a temporary condition that occurs during pregnancy. Approximately 3.5 percent of all pregnancies are affected by diabetes, which predisposes both mother and child to an increased risk for developing diabetes. All diabetics are at risk for serious complications, which are among the leading causes such as heart disease, stroke, and kidney and eye disease (Canadian Diabetes Association, 2005, February 23).

Approximately 10-15% of Canadians have insulin dependent diabetes (type 1), which is most commonly detected in children and adolescents. It is a chronic disease for which there is no cure. In children, type 1 diabetes is caused by an autoimmune response which destroys the insulin producing cells of the pancreas and necessitates the intake of exogenous insulin for survival. This autoimmune disease is increasing in frequency worldwide, most rapidly in children five years of age. Careful disease management is essential to prevent the early onset of complications that can negatively affect their quality and longevity of life.

In October 2003, the Canadian Diabetes Association launched new clinical-practice guidelines which suggest that 2.5 million more Canadians are now at risk for non-insulin-dependent diabetes (type 2). Compared to type 1 diabetes, type 2 is more prevalent, found mainly in adulthood as a result of insulin resistance. This is a situation whereby insulin is produced, but is unable to transfer glucose into the cells. Along with adults, children are now at an increased risk for developing type 2 diabetes. At least 10 percent of youth-onset diabetes in North America is estimated to be type 2 diabetes (Canadian Diabetes Association, 2004, October 27). This is believed to be partly due to the fact that one of the most common medical conditions of childhood is being overweight (Canadian Diabetes Association, (2004, October 27). In Canada, a new partnership has developed between the Canadian Diabetes Association and the University of British Columbia (UBC), where scientists at the Centre for Research in Childhood Diabetes (CRCD) are focused on becoming world leaders in childhood diabetes research (Canadian Diabetes Association, February, 2005).

Statement of the Problem

The purpose of the review was to understand the diabetes literature, especially in relation to children, as a theoretical backdrop linked to the development of the study. This literature review indicated that children with diabetes are best treated by a team of health professionals who specialize in this condition. Following diagnosis and stabilization of the diabetes, a team approach is recommended to teach both the parents and child about the condition, and its day-to-day management. Furthermore, the initial diabetes education received must be supplemented by readily available and accessible professional support, as well as by regular follow-up. The diabetes regime is complex and it is imperative for people with diabetes to acquire the necessary knowledge and skill in managing their condition.

The purpose of my research was to examine the way in which parents seek health services and support for their children with diabetes in the Prince George region, and whether their needs are being met. The exact number of children with diabetes living in this region is unknown, because there is no central registry for diabetes. It is assumed that most of these children are treated locally by family practitioners, pediatricians, and the Prince George Diabetes Clinic. Some parents have verbalized their need for more local resources, while others have sought for what they need directly from the Diabetes Unit at BC Children's Hospital in Vancouver.

The present research is based on a sample of parents of children 18 years of age and under, who were living with diabetes, and examined the resources sought and used by their parents to help the family manage an extremely complex health problem. The following research questions were posed:

1. What resources are available to children and parents in the Prince George region?
2. What are the demographics and diabetes history of children with diabetes and their families within the Prince George region?
3. How do these children compare to others described in the literature?
4. What services and support systems are parents utilizing?
5. Are existing resources meeting the needs of parents and their children with diabetes?
6. In what way are existing services not meeting the needs of parents and their children with diabetes?

7. What suggestions do parents have to improve the availability and/or accessibility of resources/services?

Definitions of Terms

The central terms used in this study were defined as follows:

1. EATING DISORDERS: Anorexia nervosa and/or bulimia.
2. EPIDEMIC: A condition affecting many people within a given area.
3. HEMOGLOBIN A1c (HbA1c): A blood test that indicates the average blood sugar level in the preceding two to three months. It measures the attachment of glucose to the hemoglobin molecule.
4. HOME BLOOD GLUCOSE MONITORING (HBGM): An invasive procedure performed by the patient at home to check the current blood sugar level with the use of a glucose monitor.
5. HYPERGLYCEMIA: A blood sugar level above the normal range. It can be life threatening.
6. HYPOGLYCEMIA: A blood sugar level below the normal range. It can be life threatening.
7. KETOACIDOSIS: A serious, acute acidotic state commonly associated with hyperglycemia.
8. INSULIN SHOCK: A serious acute state resulting from hypoglycemia.
9. NEPHROPATHY: Disease of the kidneys.
10. NEUROPATHY: Disease of the nerves.
11. RENAL FAILURE: Failure of kidney function.

12. RETINOPATHY: Disease of the eyes due to changes in the retinal blood vessels.

Focus of the Review

As mentioned previously, the three main types of diabetes are type 1, type 2, and gestational. The following issues are reviewed: approaches to the management of diabetes (nutrition therapy, physical activity, insulin therapy in type 1 diabetes, pharmacologic management in type 2 diabetes, and complications), Type 1 diabetes in children and adolescents (incidence and prevalence, characteristics, Type 2 diabetes in children and adolescents, growth and development considerations (diabetes in the neonate and infant, diabetes in the preschooler, diabetes in the school-aged child, diabetes in puberty and adolescence), complications of diabetes in childhood, and family issues. I conclude the chapter with a brief analysis and summary.

There are two other topics that are of importance within the Prince George region: diabetes in aboriginal people in Canada, diabetes and pregnancy (pre-existing diabetes and pregnancy, gestational diabetes). As these topics do not directly relate to parents with diabetic children, this material is placed in Appendix 4.

Type 1 Diabetes in Children

Incidence and Prevalence

Type 1 diabetes is the most common endocrine disease in children and adolescents. The disease is increasing in frequency worldwide, particularly in children five years of age (Sperling, 2005). The disease is uncommon in China, India, and Venezuala, common in Sardinia and Finland, and increasing in incidence in Norway, Sweden, and Finland. The exact numbers are unknown since a central registry for diabetes is not mandatory. The available data indicates that over 900 children are followed annually by the Diabetes Management Program at the British Columbia Children's Hospital (Hatton, 1992). In a recent publication by the Ministry of Health Services, it is stated that 2,217 British Columbian children aged 18 and under are living with diabetes. Various sources indicate the incidence may be increasing worldwide. While the 1989 British Columbian prevalence rate was 1/600 children, there has been a steady increase over the years with an overall incidence rate of 8-16/100,000 per year (Hatton, 1992). A recent study completed in Edmonton, Alberta (Toth, Lee, Couch, and Martin, 1997), cites a rate of 24.3/100,000. This calculation may be the highest rate in North America, and there is concern among researchers that the actual rate may in fact be higher. Although the overall incidence of diabetes in children is not high in comparison to other conditions, the chronic nature of the disease, its complex management, short and long term complications, and increasing trend demand a greater attention focus.

Characteristics

Type 1 diabetes is a chronic disease in children. It affects males and females equally, has a peak onset at the age of five and seven years and puberty, and incidence rates are higher in autumn and winter (Sperling, 2005). The etiology is thought to occur when the child has a genetic predisposition to the disease, which is then triggered by viral and/or environmental factors. The resulting immune response destroys the beta cells of the pancreas that produce insulin. Autoantibodies are present in 70% to 80% of patients newly diagnosed with the disease. Increased risk is associated with prenatal rubella and islet related autoantibodies that have been detected after mumps, measles, chickenpox and rotavirus (Sperling, 2005). Without insulin, the body cannot metabolize glucose for energy, resulting in hyperglycaemia as well as an alteration in protein and fat metabolism. The child presents with polyuria, polydipsia, lethargy, and develops recurrent infections such as boils, abscesses, urinary infections and thrush due to high blood glucose levels. Weight loss occurs as the body utilizes body fat for energy. The breakdown of fats results in increased ketone bodies that may lead to metabolic acidosis and without treatment the child may become comatose. The diagnosis is confirmed by a random plasma glucose level above 11.1mmol/liter, or a fasting plasma glucose level above 7.0 mmol/liter.

The treatment and management of a child with diabetes is complex and demanding and requires realistic goals for each child and family. Factors that need to be considered include the patient's age, developmental status, family involvement, social and economic factors (Sperling, 2005). I am personally aware of the management of diabetes in children and have included some of them. A specific diet is no longer recommended. Treatment includes insulin replacement (usually two or more injections per day calculated at 1-2units/kg. of body weight), regular blood glucose monitoring, a sugar restricted healthy diet, and exercise (at least 30 to 60 minutes at least five times a week). Blood glucose levels should be monitored approximately four to six times a day and be kept between 4 and 8 mmol/liter, except for the toddler and younger child, which should be 6-12 mmol/liter, due to the potential negative effects of hypoglycaemia on the developing brain. Haemoglobin A1c should be done every 3 months and maintained below 8.5%. Regular visual screening is also important in the child with diabetes since vision problems are common. While a few children develop cataracts early in the disease, both hyperglycaemia and hypoglycaemia cause visual disturbances which may improve with metabolic control. Blood pressure also needs to be checked each visit, since hypertension occurs in 45% of diabetics and needs to be treated to preserve renal function (Grey & Kanner, 2000). The patient's urine should be checked for microalbumin on a yearly basis to assess renal function.

Children and adolescents with diabetes are at risk for the usual childhood illnesses as their peers. Consequently, children with diabetes should be immunized and receive the yearly influenza vaccine to decrease the risk for developing complicated influenza illness. Stressors such as infections can cause the blood sugar to rise and possibly lead to DKA. With symptoms such as vomiting and diarrhoea, blood glucose testing may have to be done more frequently, and although dietary intake may be decreased, insulin requirements may increase. During times of illness, parents may need to contact the child's paediatrician and/or diabetes team for direction and guidance.

Maintenance of near normal or normal blood glucose levels is necessary to prevent short and long term complications. Life expectancy for children with diabetes is approximately 20 years less than for those without diabetes, due to the long term complications of the disease (Grey & Kanner, 2000). Complications can include blindness, renal failure, painful neuropathies, cardiovascular disease and death. Forty percent of affected individuals experience renal failure and 50% diabetic retinopathy after 15 years (Grey and Kanner,). Although complications may not be totally eliminated, with good control the onset and progression can be delayed.

Growth and Development Considerations

The onset of type 1 diabetes in children is most common in late childhood and early adolescence, although infants three weeks and younger have been diagnosed with diabetes (Hatton, Canam, Thorne, & Hughes, 1995). The disease's nature presents children and parents with challenges far beyond simple day-to-day management. Complications with usually minor illnesses, such as flues and diarrhoea, can become serious; moreover, growth and development, which may be slowed in some cases, demand continuous modification of the treatment regime. All of these events require adjustments, perseverance, knowledge, skill and adequate coping behaviours. Optimal management requires cooperation between the health care team and the family. Members of the team should include the family, physician/paediatrician, nurse educator, dietician, and social worker.

Diabetes in the Neonate and Infant

Neonatal diabetes which occurs in the first month of life is very rare. Complete remission occurs in some cases in weeks or months after diagnosis; however, about one third to one half of the patients remain permanently diabetic (Cashin & Briars, 1999). The diabetes may also recur in late childhood or adolescence. Many of the neonates are small for gestational age and present with hyperglycemias and severe dehydration at the time of diagnosis. The aetiology has been suggested to be a rare genetic condition or congenital aplasia of the pancreas, islets, or beta cells (Golden, 1999).

The immediate goal for treatment of the neonate diagnosed with diabetes is to correct the dehydration and hyperglycaemia. Once stabilized, treatment includes administration of insulin, frequent and careful blood glucose monitoring, and adequate nutrition for proper growth and development. Insulin requirements are based on blood glucose readings and may have to be diluted due to the very small amounts. Frequent dosage adjustments may be necessary as a result of rapid growth.

As with the neonate, the young infant also presents unique concerns in maintaining control, and is extremely vulnerable in relation to management of the disease. Observations, in addition to glucose readings, may be the only indicators of problems which may be quite subtle in the early development of short-term complications such as ketoacidosis and hypoglycemia. Parents must be taught to recognize the signs and symptoms of hypoglycaemia: jitteriness/tremors, apnoea, lethargy/limpness, irritability, poor feeding, vomiting, cyanosis, respiratory distress, and/or eye rolling (Cashin & Briars, 1999). If this situation occurs, parents should test the infant's blood glucose and administer a fast acting carbohydrate. Glucagon should be given and 911 called if the infant is seizuring or unconscious. Severe and/or recurring hypoglycaemia should be avoided if at all possible, particularly in children under 3 years of age, because the brain is still developing and is more susceptible to permanent injury. Research has shown that overly rigid control of blood sugars can cause severe hypoglycaemia in the young child, and may result in adverse effects on brain development (Diabetes Control and Complications Trial Research Group, 1994).

The parents of an infant with diabetes require a great deal of support and education to cope and adapt. They may be fearful and upset about inflicting pain when giving their baby injections and conducting blood glucose testing. Once the newborn is home, the parents may initially need to call the clinic daily with blood sugar readings and possible insulin adjustment. Follow-up by a home care nurse experienced in paediatric diabetes and infant care would also be advantageous. Studies are ongoing related to the possible potential protective effects of breastfeeding and early exposure to cows milk on the incidence of autoimmunity and type 1 diabetes (Sperling, 2005).

Diabetes in the Preschooler

There are a number of characteristics of diabetes in the pre-school years that are unique and need to be considered in management. Eating and activity patterns change and become somewhat erratic. The child may not willingly accept dietary restrictions, and should not be forced to eat since this may cause anxiety and frustration for all involved. The rapid onset insulin, Lispro can be particularly helpful in this age group, because it can be given after eating based on the current blood glucose level and actual food intake. In addition, the child offers more resistance to the finger pokes required for home blood glucose monitoring (HBGM), as well as the insulin injections, necessitating that parents become more creative and innovative in obtaining cooperation. The child may even perceive the treatment regime as punishment. The preschooler is usually unable to perform diabetes tasks independently, but by age 4 should be able to cooperate with the regime.

As with the infant, it is important to set reasonable blood glucose goals to minimize or prevent hypoglycaemia. Children who develop diabetes during the preschool years are at increased risk for developing learning disabilities and attention difficulties (Golden, 1999).

Two other problems that preschoolers with diabetes may experience are nightmares and enuresis. Parents must check the child's blood sugar to determine if the nightmares are a result of hypoglycaemia. If hypoglycaemia is the suspected cause, then adjustment of diet and insulin should prevent further episodes. Also, a number of children experience enuresis at the time of diagnosis. Children who were previously dry, should be told it is due to diabetes and will subside once the diabetes is controlled. However, enuresis can also occur with well-controlled diabetes.

Diabetes in the School-Aged Child

The school-age years (6 – 12) present children with their own challenges as they enter the school system and are less closely monitored. The younger the child, the more supervision is required; but for all ages, schools need to be prepared to treat hypoglycaemia and provide the ability to do blood glucose testing and administer insulin. The diabetic regime should be organized so that it does not interfere with academic and extracurricular activities. Older children must be taught to prevent hypoglycaemia, especially when exercising, by eating a snack beforehand and carry glucose with them at all times. The child must also take food along on school day trips in the event they may experience hypoglycaemia. Increased sports activity and eating away from home require special planning, including ensuring that the child's "crash pack" is always available in case of a hypoglycaemic episode.

Parents now have the additional responsibility of educating teachers and day- care providers about their child's needs, and maintaining close contact in order to ensure adherence to the medical regime. The child should be able to participate fully and safely in the school experience. School and day care personnel must be trained in the treatment of diabetic emergencies. Studies have shown that school personnel do not have a good understanding of diabetes and parents of children with diabetes lack confidence in their teachers' ability to manage diabetes effectively (American Diabetes Association, 2003). It is therefore recommended that diabetes education must be targeted toward day care providers, teachers, and other school personnel who regularly interact with the child (American Diabetes Association, 2003).

As the child spends increased time away from home, teaching self-care activities and educating others who interact with the child attains paramount importance. Some of the self-care activities can be assumed by the child at this age. However, parents teach best by being involved, encouraging step-by-step assumption of responsibility by the child, and providing care and support when needed. Children at this age may be able to perform simple technical tasks, but do not have the cognitive ability to make decisions about insulin dose, diet and exercise. The process of self-care should be gradual, with continued parental guidance and support.

Diabetes in Puberty and Adolescence

The onset of puberty and adolescence heralds the emergence of problems not previously experienced for both parents and youths. The presence or onset of diabetes can greatly magnify the emotional and psychological difficulties experienced by teens without a chronic condition. The insulin resistance that develops, and competition between puberty hormones and insulin for cell entry, result in elevated and fluctuating blood sugars. Non-compliance with some or all aspects of treatment and parental conflict are common occurrences, resulting in elevated blood sugars and haemoglobin A1c readings above the acceptable range of 8%. Some additional and serious problems that may surface at this stage of development, more so than in the non-diabetic teen, include depression, eating disorders, and the withholding of insulin as a measure to control weight (Day, 1997; Diabetes Control and Complications Trial Research Group, 1994; Kovacs, Goldston, Obrosky, & Bonar, 1997). It is not unusual to witness short-term complications occurring with greater frequency, but this is also the time when long-term complications become apparent. The onset of long-term complications is not unusual in the individual who has had type 1 diabetes for 10 years; however, this situation can be accelerated with poor control. Unfortunately, this stage of development can be a great source of stress for both parents and teens, and the need for positive intervention cannot be overstated.

The goal of treatment should attempt to normalize blood glucose levels. Visits with the multidisciplinary team and phone consultations should be frequent. Insulin may need frequent adjustment based on blood glucose readings, diet and activity. Some teens find it difficult to accept and maintain an intensive treatment regime. It is also at this time that there is a gradual transition in which the teen optimally assumes more self-care, both for the diabetes care and other aspects of their lives. However, teenagers are not able to assume the complexities of diabetes care completely on their own, and continued positive support and guidance from the health care team and parents is of paramount importance.

Some teens experience recurring life-threatening episodes of ketoacidosis (DKA) due to extremely poor metabolic control. The cause may be due to inadequate medical care, inadequate basic education or intentional insulin omission. Very poor control is dangerous and preventable. The adolescent and family may need to be assessed regarding depression and psychosis, and may need psychotherapy and psychiatric treatment. Children and adolescents with diabetes have been found to have a higher rate of psychosocial problems, such as low self-esteem and depression, than their peers, however, adolescents have more problems with metabolic control and behavioural adjustment than do younger patients (Grey, Lipman, Cameron & Thurber, 1997).

Because type 1 diabetes is a metabolic disorder affecting carbohydrate metabolism, it can affect the child's growth and development. Children and adolescents with less controlled diabetes may fail to grow normally; in particular, the onset and progression of puberty may be delayed. In girls, menarche may be delayed, and if regular menses cease, then metabolic control should be investigated. Height and weight should be checked at each medical and clinic visit and be compared to growth norms.

Weight issues can be of particular concern in the adolescent with diabetes. Obesity can occur in children and adolescents, particularly if they are on intensive regimes, which increases the risk of becoming overweight by 73% (Grey & Kanner, 2000).

Another concern is the increased frequency of eating disorders in adolescent girls. Although some girls use non-insulin methods of losing weight such as decreasing their caloric intake, self-induced vomiting and laxative abuse, others reduce or omit their insulin. Manipulating insulin is an easy way to lose weight, but has also been associated with early development of retinopathy (Golden, 1999). Treatment includes both adequate insulin and food intake, and may require psychotherapy. Screening should include non-judgemental questions about weight, binge episodes and insulin omission for the purpose of weight control.

About the age of 18, adolescents are discharged from the paediatric diabetes clinic. Approximately 25% to 65% of young adults have no medical follow-up during the transition from paediatric to adult care. Those patients who are non-compliant with medical follow-up have poorer metabolic control (Frank, 1996). These adolescents usually attended the paediatric clinic less frequently in the final year, and were more likely to attend without a parent. Unfortunately, they required more hospitalization for diabetes problems such as DKA both prior to, and following, discharge. Reasons cited for the failure to follow-up were that they felt well and were not ready to comply with the physician's regime. Poor metabolic control and its ramifications require that adolescents be identified to ensure a smooth transition to adult care.

Two other issues that may need to be addressed are smoking and contraception. Anti-smoking counselling is important as it is a risk factor for both macrovascular and microvascular complications. Contraception and sexual health teaching may also be necessary as pregnancy in females with type 1 diabetes and sub optimal glycemic control results in higher risks of maternal and fetal complications.

Complications of Diabetes in Childhood

Most complications do not affect children. However, education and treatment may prevent or delay the onset of complications. The primary pathogenic factor in the development of complications is hyperglycaemia.

Diabetic retinopathy is rarely seen in children less than 10 years of age, but the prevalence rate increases sharply after five years duration of diabetes in post-pubertal individuals with type 1 diabetes. Screening is recommended by an ophthalmologist annually five years after onset of diabetes in individuals 15 years of age and older. Two common treatments currently used for retinopathy are vitrectomy and laser therapy. While a few children develop cataracts early in the disease, both hyperglycaemia and hypoglycaemia can cause visual disturbances which may improve with metabolic control.

Nephropathy is rare in prepubertal children with diabetes. Annual screening for microalbuminuria, the first sign of diabetic nephropathy, should begin with the onset of puberty. Persistence and/or progression of microalbuminurial in adolescents is usually treated with ACE inhibitors, however, good glycemic control with intensive insulin therapy is imperative. End stage renal failure may occur many years later and requires dialysis or kidney transplantation.

If present, neuropathy is subclinical in children. Screening is not necessary until adolescents have had type 1 diabetes of at least five years duration. Peripheral altered pain sensation, superficial or deep, usually at night, may occur. Glycemic control and tricyclic antidepressants may improve symptoms.

Hypertension occurs in 45% of all diabetics and needs to be treated to preserve renal function (Grey, & Kanner, 2000). Children and adolescents should have routine blood pressure measurements, and persistently high readings should be treated.

Children and adolescents with type 1 diabetes have a higher frequency of dyslipidemia than their peers without diabetes. Dyslipidemia in adolescents and adults with type 1 diabetes is associated with a higher frequency of progressive microalbuminuria, retinopathy and macrovascular disease. The cause is felt to be due to poor metabolic control and can be reversed with intensification of therapy.

DKA is an acute complication and occurs in 15 to 67% of patients with new onset diabetes (Canadian Diabetes Association, 2006). It usually occurs due to failure to take insulin or poor sick day management. The lack of insulin results in fatty acid metabolism and acidosis. Most cases are treated without complications; however, up to three percent are complicated with cerebral oedema which has a 21% to 24% mortality rate (Canadian Diabetes Association, 2006). Treatment consists of hospitalization, administration of insulin and rehydration.

Hypoglycaemia, which occurs when the blood glucose level drops below 70 mg/dL, is the most common acute complication associated with the treatment of type 1 diabetes. Children and parents fear severe hypoglycaemia because it can result in seizures, loss of consciousness, and possible development of permanent brain dysfunction. Exercise can cause hypoglycaemia during the activity and several hours later, also young children are at risk because of variable eating habits. Severe hypoglycaemic events usually occur at night. Symptoms of hypoglycaemia include shakiness, hunger, anxiety, palpitations, sweating, dizziness, irritability, crying, sleepiness, headache, mental confusion, and pallor. To prevent hypoglycaemia it is important to ensure a regular intake of well balanced meals and give carbohydrate foods while exercising or decrease the short acting insulin. Mild to moderate hypoglycaemia is usually treated with glucose tablets or a snack such as orange juice and crackers, while severe hypoglycaemia requires dextrose intravenously or glucagon subcutaneously.

Hypothyroidism and celiac disease are the most common autoimmune diseases associated with Type 1 diabetes. Treatment for hypothyroidism involves thyroid replacement with thyroxin, whereas celiac disease is managed by strict avoidance of gluten containing foods.

Type 2 Diabetes in Children and Adolescents

Type 2 diabetes used to be a disease affecting the older adult, however, in the past 10 to 15 years it has been diagnosed in children as well. These children are usually diagnosed over the age of ten years and are in middle to late puberty. They are usually overweight or obese, have glycosuria without ketonuria, absent or mild polyuria or polydipsia and little or no weight loss (Sperling, 2005). The prevalence in Canadian

Aboriginal children five to 18 years of age may be as high as 1% (Canadian Diabetes Association, 2006). Data from the United States suggests a thirty-fold increase in the number of children with type 2 diabetes over the past 10 to 15 years. In Manitoba and Northwestern Ontario, follow-up data in youth diagnosed with type 2 diabetes before age 17 revealed alarming observations of high mortality rate (9%), morbidity (eg. dialysis, blindness, amputations), pregnancy loss (38%), and poor glycemic control (Sperling, 2005).

Children and adolescents at risk for developing type 2 diabetes include: being a member of a high risk group (for example, people of Aboriginal, Hispanic, South Asian or African descent); having a family history of type 2 diabetes; exposure to diabetes in utero and being overweight; and a diagnosis of polycystic ovary syndrome, acanthosis nigricans, hypertension or dyslipidemia. Obese children greater than 10 years of age should be screened for type 2 diabetes every two years if they meet two of the above criteria.

Children with type 2 diabetes should receive care by an interdisciplinary pediatric diabetes team. Complications such as retinopathy, which can lead to blindness, affect 33% of people with type 2 diabetes. The longer the duration of diabetes, the higher the glycosylated hemoglobin (A1c), and the higher the blood pressure, the more likely the progression of retinopathy. If hypertension is present, then the development and progression of retinopathy can be reduced with antihypertensives. The child's eyes should be tested by an ophthalmologist at the time of diagnosis and follow-up that is dependent upon the severity of retinopathy.

Lifestyle modification is the preferred treatment for children with type 2 diabetes. However, adolescents may need metformin, which reduces insulin resistance, or insulin, if glycemic targets are not achievable. Obesity is a major modifiable risk factor for the development of type 2 diabetes, yet studies on the prevention of obesity in children are limited. Dr. Hanh Huynh, a professor from the University of Northern British Columbia, is currently doing a study to try to identify potential children that have risks of developing type 2 diabetes. The main factor being considered is obesity. Input will be sought from students in grades one to six regarding sports or games they like to play. Also questions about lifestyles will be asked to try and find factors leading to type 2 diabetes. A group of students will have waist and hip circumference measurements taken and will be followed for a period of five years. Dr. Huynh states the focus of the research is the increased rate of childhood obesity and type 2 diabetes (personal communication).

Family Issues

Family coping styles when confronted by chronic disease in a child vary widely, but families nonetheless are faced with a serious stressor. Numerous studies (Gallo, 1990; Knafl, Breitmeyer, Gallo & Zoeller, 1996) describe the severe stress that a child with a chronic condition brings into the family situation. According to Knafl, Breitmayer, Gallo, and Zoeller (1996), family management styles fall on a continuum ranging from thriving to floundering, with intermediate stages of accommodating, enduring, and struggling. Management and control is undoubtedly within each family's realm of responsibility. However, the phrase so commonly heard recently of "giving the control back to the family," must be viewed in the context that families usually need help to assume control. It may be difficult to operate successfully in isolation; as a result the initial and ongoing assistance and support of the health care team must be sustained. Unfortunately, some studies (Hatton, 1992) indicate that goals related to the treatment of diabetes between parents and health care professionals may at times conflict, which in turn might be the root of problems related to communication and treatment failure. This situation would be serious for all involved because diabetes in children is not a static condition. Diabetes often takes an unpredictable course as the youngster grows and develops, with each stage challenging the coping, knowledge and skills of all family members.

Some children refuse to follow all or part of the diabetic regime, which could increase the anxiety and depression the parents may be already experiencing. Even discipline becomes an issue as the parent tries to determine if the behaviour is simply unruly, or related to hypoglycaemia. For the child on intensive treatment regimes that increase the risk of hypoglycaemia three to four times, the parents worry about normal activities such as sports, going on field trips, or overnight visits. With all the changes that occur, counselling may be helpful to the emotional health of the family and physical health of the child.

The child's health may be affected by an unstable family environment. Mothers in particular may experience increased stress due to the diabetes and might be prone to depression. A helpful approach in the management of diabetes is to maintain a sense of normalcy and routine. The diabetic child's daily regime should be incorporated into the family's own lifestyle in order to achieve the best long-term outcomes. Ideally, this may result in the child perceiving himself as healthy despite a disease diagnosis, and result in positive interactions with healthy peers and participation in age appropriate activities. Normalcy in the family is also enhanced when parents support each other and share illness related responsibilities. Parents may also benefit through membership in a support group where others share their experiences and understand their feelings. Parents also require some leisure and relaxation time, situations where relatives and friends might be able to help out.

It has been suggested that early intervention programs, combined with the standard education, support, and intensive psychosocial services provided at the time of diagnosis have a positive effect on adherence and glycemic control (Mitchell & Beth, 1996). The increased risk of mental health problems in families where a child has a chronic illness may be prevented with appropriate organization and comprehensive health services. A study examining the aspects of care-giving that parents value indicates high standards for issues such as continuity and consistency of care givers, parent involvement in decision making, education/information, and accessible and available care (Baine, Rosenbaum & King, 1995).

Brief Analysis and Summary

There are few studies on children with type 1 diabetes, not only in Canada, but also worldwide. A new World Health Organization (WHO) program, known as the Multinational Project for Childhood Diabetes (Diabetes Mondiale or DIAMOND), has been initiated to gather a variety of global data on diabetes in children over a 10 year period (1990-1999) (WHO DIAMOND Project Group, 1990). In Canada, registries have been established in Toronto, Montreal, and Prince Edward Island. Their long-term goals of the program are to find ways to prevent the disease and its complications. The increasing global incidence of type 1 diabetes, accompanied by an increased risk of mortality and death within a few years in developing countries, has stimulated this project's implementation.

The results of a recent and important study, the Diabetes Complications and Control Trial (DCCT), have contributed invaluable information for the existing body of knowledge of type 1 diabetes (DCCT Research Group, 1994). This American longitudinal study was primarily directed at adults; however, it included a study of 1993 adolescents. The primary indication from the research was that good blood sugar control prevented and/or delayed the onset and/or progression of complications, particularly in relation to visual problems and renal disease. The study cites that the benefits of tight control (i.e. keeping blood sugars in the normal range) far outweigh the major drawback of an increase in the number and severity of hypoglycaemic episodes.

The DCCT study recommends a team approach be employed to treat children with diabetes, and that this team consist of nurses, dieticians, mental health professionals and paediatric diabetologists. However, although a paediatric diabetologist is an important member of the team, their inclusion may be an unrealistic expectation in those communities located outside larger health centers. The focus of the team is on education, re-education, ongoing assessment, evaluation, and assistance with modifications to the treatment regime, as well as continued follow-up. Ideally, the team should be knowledgeable regarding the medical, physical, mental, and emotional aspects of the condition, as well as how to work with families in situations where children have a complex chronic disease.

There are a number of research projects currently underway to either improve the treatment of, or to cure, diabetes. However, the results are not yet available for widespread use. Studies have shown that inhaled insulin compares favourably to subcutaneous insulin regimes. Inhaled insulin is not yet available in Canada, but if used, may take the place of regular insulin is used in conjunction with injected intermediate or long-acting insulin (Wright & Appel, 2007). However, long-term follow up is needed to determine any adverse pulmonary effects. Whole pancreas transplantation is occasionally performed, generally along with a kidney transplant, and usually considered for the patient who has major problems with diabetes control. Islet transplantation research is currently underway in Edmonton. It involves transhepatic puncture and infusion, and an immunosuppression regimen. Eleven transplanted patients have been off insulin at twenty months. Risks of the procedure and use of immunosuppressive drugs must be considered in relation to the benefits of improved glycemic control. Data on long-term follow-up is not yet available (Sperling, 2005).

A review of the literature indicated a need for a better understanding of diabetes in children. The very positive and encouraging findings are that a team effort, including family and health as well as community services, can result in optimal health in the diabetic child, with minimal progression or possibly even prevention of dreaded long-term complications and premature death. Thus, this study focused on the examination of resources available, both those utilized and those perceived as needed, by parents of children with diabetes. The family and child with diabetes are a high-risk population, and in need of ongoing assistance in the management of a complex and demanding medical regime affecting every aspect of daily living.

CHAPTER TWO: METHODS

Sample and Data Collection

The population of interest consists of parents of children 18 years and under with type 1 diabetes listed in the files of the Prince George Diabetes Clinic. This includes children in Prince George as well as surrounding region (Burns Lake, Vanderhoof, Hixon, Quesnel, Mackenzie, Ft. St. James, Valemount, McBride, and Fraser Lake). The exact number of the population is unknown, and may be difficult to determine, However the Prince George Regional Hospital Diabetes Clinic had approximately 60 children's files in the year the data were collected. For reasons of confidentiality, the clinic could not provide me with the names and addresses of the families on file, but agreed to attach name and address labels to my survey. I placed the survey, self-addressed reply envelope, and participant cover letter in a stamped envelope which the clinic addressed and mailed out, thus maintaining anonymity(Appendix 1). From the initial 60 surveys that were mailed, 20 were completed and returned. I had coded the return envelopes and therefore was able to prepare a reminder letter to the 40 parents that had not responded(Appendix 1). Again, the Prince George Diabetes Clinic addressed and mailed the letters for me. Seven more surveys were completed and returned, for a total of 27. The survey instrument is in the appendix section of the paper. There are four parts to the survey (Appendix 2): Part A. Demographics; Part B, History and Current Status of the Child's Diabetes; Part C, Utilization and Seeking of Services and Information; and Part D, Satisfaction with Available Services and Information.

Study Design

This study is primarily descriptive and includes a collection of mainly quantitative and some qualitative data. Data was obtained with the use of a mail- in survey, in a structured format, using both open and closed questions. The survey was directed at the participating parent(s) or the person primarily responsible for the daily management of the child's diabetes. The survey includes the following topics:

- Demographic data
- The history and current status of the child's diabetes
- Resources and services sought
- Frequency of seeking health services and information
- Satisfaction with availability and accessibility of resources and services
- Explanation of reasons for dissatisfaction
- Suggestions for improvement of resources

A pilot study was initially conducted to increase validity of the survey instrument. Four local parents of children with diabetes were asked to complete the survey. Specific feedback was requested as to the length of time required to complete it, clarity of instructions and questions, and overall layout of the survey. Completing the survey took an average of 40 minutes. Several suggestions were made to clarify a few questions and to write out two acronyms. The feedback was subsequently used to modify the survey.

Data analysis includes descriptive statistics supplemented with comments from parents. The data were tabulated and analyzed using Microsoft Excel. The data from the open-ended questions were categorized by themes and described. Examples of questions included: What percentages of parents are using and satisfied with local services? Is there a relationship between a need for increased assistance and a particular developmental stage, age, or gender? What types of services are viewed as being most beneficial and are being sought most frequently? Are there any particular frustrations that parents encounter when seeking help to care for their children? Are there omissions that parents can identify that would help them cope more effectively? The results of the study will be made available to the participants, the staff at the diabetes clinic, and any paediatrician who was interested in the findings, as well as the local branch of the Canadian Diabetes Association (CDA).

Comments from health professionals, both locally and in Vancouver, had suggested that the number of children with diabetes in this area may be higher than surmised. Interest in the results from the study has been verbalized by a local paediatrician, diabetes educator and the local branch of the CDA. The data reflected patterns related to seeking and utilizing health services, as well as suggest ways that local resources could better meet the needs of children with diabetes and their parents.

CHAPTER THREE: RESULTS

Sixty surveys were mailed out to parents of children with type 1 diabetes and 27 were completed and returned, for a return rate of 45%. The following are the results of the surveys.

Demographics

The percentage of female and male children were equal, 13(48%) were female, and 14 (52%) were male. All but one child were enrolled in school, 14 in primary and elementary school, and 12 in high school. The ages ranged from three years and six months to 18 years. The average age was 13 years and three months: 44% were 12 years and under, and 52% were adolescents (13-18 years). The majority of families lived in Prince George (89%), two were from Quesnel and one was from Fraser Lake. The length of residence ranged from three and one-half years to 40 years, with an average of 18.3 years. Twenty-five (93%) of the children had siblings, 14 had one sibling, 10 had two siblings, and one had four siblings.

Eighty-nine percent of the children lived in two-parent families, seven percent (two) lived in a one-parent family and one child lived with a guardian. The mothers' age range was 33 – 55 years of age, with an average of 41. Ninety-six percent of the mothers had completed high school, and 63% had a post-secondary education. Occupations encompassed a wide range and included education, health care, sales, management, and one of the mothers was a physician. Three of the mothers were homemakers. The age range of the children's father or guardian was 34 to 60 years of age, with an average of 42.5. Eighty-eight percent had finished high school, and 56% had some level of post secondary education. Occupations ranged from trades, education, forestry, law, to self-employed. Forty percent of the children were Canadian, while 32% were of Canadian/European descent. Three children were of European descent, two East Indian, one First Nations, and one German/American.

The History and Current Status of the Child's Diabetes

Most of the children, 59%, were first diagnosed during the elementary school-age period (6 to 12 years), 30% in infancy and preschool, and 11% in adolescence. Seventy-four percent have had diabetes for five years or less and 26% had the disease from 6 to 12 years. Forty-eight percent of parents reported that the child had been ill prior to the time of the diagnosis of diabetes. Forty-one percent indicated that the child had had the flu or a cold prior to the diagnosis. Also, one of each of the following was reported: "weird rash in hot spots;" high fever; tired; and chickenpox. Sixty-seven percent of the children were sick at the time of diagnosis. Of this group 56% had weight loss, thirst and fatigue. Twenty-eight percent had frequent urination and 11% experienced thrush, mood swings, pallor and irritability. The following symptoms only occurred once in the group: excess eating, not eating, barely conscious, sore eyes, sunken eyes, and nocturia. Only one child was diagnosed in each of January and March, while two or three children were diagnosed in each of the other months.

All parents and children received diabetic teaching at the time of diagnosis: 85% at the PG Diabetes Clinic, seven percent at the BC Children's Hospital, one child at the Victoria Hospital and one child at the doctor's office. The teaching was done by the Diabetes Nurse in 48% of the cases, Dietician and Diabetes Nurse 30%, Diabetes Nurse and paediatrician 11%. One case each of nurse/doctor/paediatrician, nurse/doctor, and paediatrician. The amount of teaching done varied greatly from a few hours to 14 days.

The average number of days taught was seven. Eighty-eight percent felt they had a sufficient amount of education/teaching.

Sixty-two percent of the children had one or more relative(s) with diabetes. Seventy percent of these children had grandparents and/or great grandparents, or great aunts and uncles who had type 2 diabetes. Meanwhile 29% have relatives such as a father, sister, aunt, uncle, cousin, with type 1 diabetes.

The range for frequency of home blood glucose testing ranged from one once a day to eight times a day, however 68% tested between four to five times a day and 16% tested three times a day. Fifty-six percent of the children took insulin once a day, 28% three times a day and eight percent four times a day. Two adolescent males used the insulin pump. Seventy-eight percent of the children wore a medic alert. All parents but two knew the results of their child's HgA1c. The mother was the key caregiver in 59% of the families, while in one third of the cases the mother and father shared the responsibilities. In one situation a guardian and in another a grandmother was the primary caregiver.

Many parents experienced frustration when managing their child's diabetes, 30% frequently and 63% occasionally, although seven percent did not. The two most common groups those parents found challenging in managing the diabetes were the male adolescent at 26% and the female child at 18.5%. Management issues parents cited as problematic varied. However, three common ones included insulin injections, performing and dealing with blood sugars, and emotional and management issues with teens. Three main concerns in the school-age group included maintaining control at 53 % (i.e. keeping blood sugars in the normal range), activity/exercise at 33%, and emotional reactions at

27% (to treatment and disease). In the adolescent group four major areas were identified: maintaining control at 58%, emotional reactions at 58%, compliance with regime 33%, and diet at 33%.

Sixty-six percent of respondents indicated that the costs involved with diabetes were a financial burden. Thirty-three indicated that the diabetes was not a financial burden: however, three out of nine respondents noted that health care benefits were helpful. Eleven percent of parents reported receiving tax benefits related to their child's diabetes.

Utilization and Seeking of Services and Information

Parents of children with type 1 diabetes reported using a variety of resources for direct care and information, as well as community resources available for people with diabetes. These resources and the frequency of use are documented in Table 1.

Table 1

Frequency of Use of Services for Direct Care

Services	Never	Yearly	2-3x/yr	Every 2-3 months	Monthly
PG Diabetic Clinic	2	8	7	7	3
BC Children's Hospital	19	3	2	1	
Pediatrician	4	2	3	13	5
Family Doctor	4	9	9	3	2
Emergency	19	8			
Pediatric ward	22	5			
Public Health Unit	27				
Counsellor	23		1		2
Psychologist	26				1
Ophthalmologist	11	13		1	
911 Emergency Service	26	1			
Social Services	27				
Pharmacist				1	

Most of the families, 93%, visited the Prince George Diabetic Clinic. Of the two that did not, one was from Quesnel and the other used BC Children's Hospital. Three children visited the clinic quite frequently, that is, monthly: an eight year old boy who had diabetes for two years; an eight year old girl who had diabetes one year; and a 13 year old girl who has had diabetes for three months. Twenty-two percent of the children visited BC Children's Hospital, generally, children were referred when some type of complications had occurred. Eighty-five percent reported seeing the paediatrician as well as the family doctor, which is very positive since the paediatrician is the most knowledgeable about diabetes in children. One-half of the children that visited the paediatrician did so every two to three months. The children visited their family doctor less than the paediatrician, one-third yearly and one-third did so two to three times per year. Thirty percent of the families reported using the emergency ward on a yearly basis, while only 18% had to be hospitalized approximately once a year. Fifteen percent of the children saw a counselor: two of those were adolescents and two were of school age. Only one child, an eight year old girl, visited a psychologist. Fifty-one percent visited an ophthalmologist on a yearly basis, except for one child who sees the ophthalmologist every two to three months. The emergency service 911 was used by one child on a yearly basis; however, three parents indicated they had used this service once in the past.

Use of Services for Information

Parents used a variety of resources to obtain information to help them care for their child with diabetes. Table 2 outlines the resources utilized by parents.

Table 2

Frequency of Use of Services for Information

Services	Never	Yearly	2-3x/year	Every 2-3 months	Monthly
PG Diabetic Clinic	2	6	10	6	3
BC Children's Hospital	21	6			
Pediatrician	9	1	6	7	3
Family Doctor	10	9	4	2	1
Pharmacist	9	4	3	6	4
Library	20	1	5	1	
Internet	10	2	8	3	2
Dietician Hot Line	25	1	1		
Conferences	12	11	4		
Magazines, Journals	5	4	10	4	4
Canadian Diabetes Association	8	9	6	4	
Social Worker	27				
School Nurse	25	1			1
Public Health Unit	26				1
Emergency	25	2			

Most of the parents, 93%, used the PG Diabetic Clinic for information, 59% between two to three times a year and every two to three months. Twenty-two percent used BC Children's Hospital on a yearly basis. If the child is registered with the hospital, they have an excellent communication system in which a parent can phone or fax blood sugars or questions in the morning and an answer is sent back the same day. Approximately 60% of the families used their paediatrician, family doctor and pharmacist for information. Only 26% used the library for information, meanwhile 56% used the internet. Fifty-six percent of parents had attended conferences, 41% on a yearly basis, with another 15% two to three times a year. Diabetes literature was read by 82% of the parents with, 67% having done three times a year or more frequently. The CDA was contacted by 70% of the parents. The dietician hot line, social worker, school nurse, Public Health Unit and Emergency Department were rarely used, if at all.

The most frequently utilized professional looking after a child's diabetes was the paediatrician in 40.7% of the cases. A combination of the paediatrician, diabetic nurse, and family doctor were used in 18.5 of cases. The diabetic nurse was used in 11% of the cases. Eighty-one percent indicated they had not had to wait for services. Only two parents indicated they had long wait times for both the diabetes clinic and paediatrician. Almost all the parents, 92%, had used the hospital emergency department or the emergency service 911 in case of an emergency.

Seventy-four percent of the parents indicated that their school had special arrangements for emergency care. However, the remainder indicated their school either did not have special arrangements or they did not know if the school had special arrangements. The majority, at 60%, were satisfied with the care received in school, although 15% were not. Four parents commented that the teachers knew little about diabetes. One comment each was made on the following: inadequate access to the emergency snack; substitute teachers unaware of the condition or special requirements; concern for child on field trips; medical information not passed on to teachers in high school; school environment not conducive to testing and injections; and health unit poor in providing protocol and instructions. None of the children had been denied participation in activities in the school or community. Of the five parents that commented on daycare or after school care, two were satisfied. The others commented that one of the children was not wanted in daycare. One parent discontinued daycare due to inadequate diet supervision, while another parent commented that it was hard to find someone with knowledge of diabetes.

Only 63% of the parents were members of the Canadian Diabetes Association and 47% attend at meetings. Four parents stated they did not attend meetings because they were primarily geared to adults with type 2 diabetes. Approximately half of the children attended the Diabetes Camp at Gibsons annually, of the ones that did not, half indicated they did not like it. If the Activity Group for eight to 13 year olds was re-established, 41% indicated that they would participate, while 44% were outside the age limit. If the Parents of Children with Diabetes Group were started up again, 51% said they would participate, 41% cited time commitments as reasons for not attending. These parents indicated that the most helpful support system was family and friends.

Satisfaction with Available Services and Information

Parents of children with type 1 diabetes had a variety of services and information available to them to help them care for their child. The following are responses of parents with children with type 1 diabetes in relation to satisfaction with services and sources of information.

Eighty five percent of the parents indicated they were somewhat or very satisfied with the PG Diabetic Clinic. Only one was somewhat dissatisfied and one very dissatisfied. Of the 12 families who had visited BC Children's' Hospital, 8 were satisfied with the service provided, and 4 had expressed neither satisfaction nor dissatisfaction. Seventy percent of the respondents were somewhat and very satisfied with their paediatrician, only one was somewhat dissatisfied and one very dissatisfied. Fifty-five percent of parents were somewhat to very satisfied with their family doctor, and two were very dissatisfied.

Table 3

Satisfaction with Services and Information

Services	Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied	N/A
PG Diabetes Clinic	1	1		4	19	1
BC Children's Hospital			4	3	5	14
Pediatrician	1	1	2	8	11	3
Family Doctor	2		3	7	8	5
Emergency	1	3		6	7	9
Pediatric ward	1	1		7	11	6
Public health unit	1		2		1	21
Counsellor			1	1	2	21
Psychologist			1		1	23
Social Services			2			23
School Nurse		2	1	2	1	19
Ophthalmologist			1	2	12	9
911 Emergency Service			1		4	20
Teacher	2	1	3	6	4	6

Thirty-three percent of parents have not used the emergency department, while 48% are somewhat to very satisfied, and four responded as somewhat or very dissatisfied. Twenty-two percent of parents had not used the paediatric ward, meanwhile, but of those who did 67% were somewhat or very satisfied. The Public Health Unit, counsellor, psychologist and social services were rarely commented on or not at all. Fifty-two percent of the children were examined by an ophthalmologist, and all of the parents were satisfied with this service. Of the five parents who had responded to having contact with the school nurse, three were somewhat to very satisfied and two were somewhat dissatisfied. Only four parents indicated they had used the emergency service 911 and all were very satisfied. Of the 13 parents that responded to contact with their child's teacher, 77% were somewhat to very satisfied, while 23% were somewhat to very dissatisfied. Overall, 59% of the parents indicated that the available services met their needs, and 33%

stated that their needs were met somewhat There were no responses that indicated parental needs were not met at all.

Themes of Parenting Comments

Parents were asked to describe which resources/services are most helpful and how local resources could be improved to help them manage their child's diabetes.The data from the open-ended questions have been categorized by themes and described. There is no significance in relation to the order of the themes or importance or frequency of the data.

Table 4

Themes of Parents' Comments Regarding Satisfaction/Dissatisfaction with Activities/Resources for their Diabetic Children

Theme Number	Theme Label	Frequency /27
One	Satisfied with Diabetes Clinic	14
Two	Dissatisfied with Doctor	6
Three	Satisfied with Paediatrician	3
Four	Expensive	6
Five	Dissatisfied with School/Daycare	5
Six	Long wait for medical appointments	6
Seven	Need for support group	4
Eight	Teen issues	5
Nine	Helpful activities/resources	14
Ten	Inadequate/lacking activities/resources	16

In the first theme, 52%, or 14 of 27 of the respondents commented on satisfaction with the Prince George Regional Hospital Diabetic Clinic. They felt the staff was knowledgeable, helpful and easily accessible. They also found the staff to be patient, caring and friendly. Three respondents, or 11%, commented on satisfaction with pediatricians in theme three. Theme nine deals with a variety of helpful activities/resources available to parents of children with diabetes. Three respondents found BCCH very helpful, and in particular felt their 24 hour availability and a rapid response to faxes especially helpful. Two respondents found the CDA helpful, although the CDA focuses on adults with Type 2 diabetes. Three parents indicated that summer camp for children with diabetes was a good experience for their child. One respondent each felt the public library, the Dialogue magazine, Intersect and the pharmacist were helpful.

In the second theme, six of 27, or 22% of the respondents commented that doctors were not helpful and two indicated that doctors lacked knowledge of diabetes. Also, six of 27, or 22% of the respondents commented on the expense of diabetic medications and supplies in theme four. One individual stated that sometimes needles had to be reused and some days blood sugar could not be tested due to lack of funds for supplies. Another respondent indicated that without good health insurance, it would be difficult to manage. Five of 27, or 19% of responses were made regarding dissatisfaction with schools and daycare in theme five. These parents felt there should be more diabetes education in schools and better communication between parents and schools. Six of twenty-seven, or 22% of respondents cited long waits for appointments in theme six, five for the Diabetes Clinic and one for a pediatrician. One person suggested using e-mail for quick answer questions. In theme seven, four respondents, or 15%, indicated they would like to see a support group for parents. Five of 27, or 19% of respondents addressed teen issues, the only age group singled out as problematic. These parents felt that the added stress of teenage issues made it more difficult to manage diabetes.

Theme ten dealt with a variety of inadequate or lacking activities and resources. Two parents felt the diabetes clinic was not accessible enough, and one felt a hot line might be helpful. Some issues cited included discomfort leaving their child with a sitter, a need for better food labels, and a need for clearer record books and labeling of insulin cartridges. A couple of parents commented they would like to see more teaching clinics directed at type 1 diabetics and teens, and workshops showing new treatment innovations.

CHAPTER FOUR: DISCUSSION

Demographics

The gender proportion of the children in this study is consistent with the literature in that the condition affects both sexes equally. The average age of the children is 13 years, with approximately half under 12, and half over 12. The majority of children live in Prince George and have siblings, while one child has a sibling with diabetes. Most of the children live in two-parent families.

The average age of mothers of children with diabetes was 41 years, 67% had a post-secondary education, and 3 were homemakers. The average age of the father was 42.5% years, and approximately 90% finished high school, and 56% obtained post secondary education. The extent of post secondary education evident for both parents suggested there was a higher survey return rate for more educated people. This behavior was typical of many survey studies. The majority of children were of Canadian and Canadian/European descent.

History and Current Status of Child's Diabetes

Approximately 60% of the children were diagnosed during the school-age period (six to 12 years, 30% in infancy and preschool, and 11% in adolescence) which was somewhat similar to the literature that cited peak onset at age 5 and 7 years and at puberty (Hatten, Canam, Thorne, & Hughes, 1995). Forty-one percent of the children had respiratory infections prior to diagnosis, which was consistent with the literature that indicated an environmental trigger may be partly responsible for the disease. Approximately half of the children had diabetes symptoms at the time of diagnosis. In this study, there was no specific time of the year that disease onset occurred. However in the literature, incidence rates were cited as being highest in autumn and winter (Sperling, 2005).

All parents and children received diabetic teaching at the time of diagnosis, with the vast majority (85%) at the PG Diabetic Clinic, and only seven percent at BC Children's' Hospital. A diabetic nurse was involved in the teaching in almost all of the cases and a pediatrician in approximately 11% of the cases. Hatten (1992) recommends that a multidisciplinary approach be utilized in all cases. The average number of teaching days was seven. Although 88% of the families felt they had enough education/teaching, a few felt instruction had been insufficient. The literature indicates that adequate teaching is necessary for successful adaptation to the disease to occur, however no specific hours or days are recommended (Mitchell & Beth, 1996). I take the view that the amount of instruction needed varies depending upon many factors, such as the parent's and child's age, and knowledge and ability to adjust to a chronic condition requiring a major adjustment in their lives.

Sixty-two percent of the children have a relative(s) with diabetes. This is consistent with the fact that genetics may play a role in the development of the disease. Approximately 70% of the participants perform home blood glucose testing between four and five times a day, which in most cases is sufficient and which is consistent with recommendations in the literature (Sperling, 2005). Eighty-four percent take insulin two to three times a day, which is a traditional approach in treating children with diabetes. Only two adolescent males in the study use the insulin pump, which is unfortunate, since it is one of the best ways to control blood sugar. Twenty-two percent of the children do not wear a medic-alert, which could be problematic in case of an emergency such as hyperglycemia or insulin shock. Also, two parents do not know their child's HgA1c, which might make it more difficult to control the diabetes. Although it is encouraging that in one-third of the cases both parents share the responsibilities related to the care of the child with diabetes, the mother is the key caregiver in approximately 60% of the families. Caring for a child with diabetes can be stressful and demanding, therefore the literature recommends that a shared family approach is most beneficial (Sperling, 2005).

The cost of diabetes is a financial burden for two thirds of the respondents. For some, extended health care programs are helpful, however full government coverage for all diabetes medications and supplies would be helpful. These children require diabetes medications and supplies to live. And, although the pump is most effective to control blood sugar, it is too expensive for most families (the pump costs approximately $6800, and the monthly maintenance charges for the tubing and insulin reservoir are $250).

The majority of the parents in the study experienced occasional frustration and close to one-third frequent frustration when managing their child's diabetes; especially managing the male adolescent and female children. Parents indicated that the most common problems included insulin injections, performing and dealing with blood sugars, and emotional and management issues with teens. The main issues for the school-age group included maintaining blood glucose control, regulating activity and exercise, and dealing with emotional reactions. Parents with the adolescent children, also identified maintaining control and emotional reactions as problematic, as well as compliance with regime and diet.

Utilization and Seeking of Services and Information

Ninety-three percent of the children visited the Prince George Diabetic Clinic, one child that did not was followed by BC Children's' Hospital (BCCH). It is encouraging to interpret from the data that almost all the children visited the clinic, pediatrician and family doctor. Some visited one health care professional, and some all three. And although the clinic and pediatrician are knowledgeable regarding diabetes in children, the extensive team at the diabetes clinic at BC Children's Hospital deals exclusively with children with diabetes. Six of the children in this study who used local resources, also used BCCCH anywhere from 2-3 months to once a year.

Generally, children with diabetes who live outside Vancouver, are referred to BCCH when they develop diabetic problems requiring specialized care at the time of the referral and then on a follow-up basis. BCCH has a very helpful program in place for any of their patients in their system, in that parents can phone or fax problems, questions, blood sugars to the clinic and the endocrinologist at the clinic responds the same day with answers and recommendations. The children in this study sought a healthcare professional anytime from a monthly to yearly basis, many sought more that one over the year. All diabetics should have a HgA1c done every three months, hence, if there are no complications, this would be a perfect time for a thorough check-up. Five children received assistance with emotional issues: two adolescents and two school-age children see a counsellor, and an eight year old girl visited a psychologist. Also, half of the children visited an ophthalmologist on a yearly basis. The literature indicates children with diabetes should get their vision tested five years after the onset of the disease, and then yearly, unless there are complications, then visits should be more frequent. It is imperative that children with diabetes have good blood glucose control (that is within the normal level), and have their eyes tested as recommended, because diabetes is one of the main causes of blindness. In Prince George there are very few ophthalmologists and thus are very heavily booked, hence wait times may be an issue. Fortunately, the emergency service 911 was rarely used, indicating most children receive medical assistance before a critical stage occurs.

The majority of families used the same sources for information as for direct care, with the addition of their pharmacist. The pharmacist is an important member of the team because they are is knowledgeable of the child's medications as well as the various supplies the child needs. The pediatrician and diabetic nurse were cited as the main health care professionals providing care for the child. However two of the parents indicated they had long wait times to get an appointment, which could be problematic if the child was having difficulty managing the diabetes.

More than half of the parents used the internet for information and 82% read literature related to diabetes. Although 70% of the parents contacted the CDA for information, a significant number felt most of the services were not useful because they were directed at type 2, adult diabetics. The literature indicates that 90% of all diabetics are adults with type 2 which may explain the focus of services. However, an effort should be made to provide some programs for children with type 1 diabetes, even if only once a year (Canadian Diabetes Association, 2003).

Although comments regarding school issues were generally positive, four parents were dissatisfied. Some issues raised were that teachers knew little about diabetes, substitute teachers were not informed of the child's medical condition, high school teachers were not aware, children had experienced inadequate access to emergency snacks were not made available and the school environment was not conducive to testing and injections. It is relatively simple a inform the teacher at the elementary level of a child's medical condition because the child has the same teacher for most courses. However, in high school the child usually has a different teacher for each class, hence a greater effort must be made to inform all involved. Some daycare concerns included inadequate diet supervision, a feeling that the child was not wanted, and the inadequate knowledge of the daycare provider. On a positive note, none of the children had been denied participation in activities in the school or community. The key to making it a safe and enjoyable experience is to ensure the child has an adequate snack in case the blood sugar drops and requires treatment. The best approach is to be prepared for the possibility of a low blood sugar particularly for the young child, as the older child or teen is more aware of the possibility of complications. Parents must teach all people in contact with their child the potential for problems related to their child's diabetes.

Half of the children attended the Diabetes Camp at Gibsons, British Columbia each summer. The CDA pays for the whole trip. The camp is staffed with healthcare professionals who look after each child's diabetic needs. Children from all across the province participate annually in a variety of activities, including land and water sports. Some children do not attend because they do not enjoy it. If the Activity Group for eight to 13 year olds were re-established, 41% would participate, while 44% are outside the age limit. Also, half of the parents indicated they would attend a parent support group, while the other half would not due to time commitments. There have been parent support groups in the past , but they did not continue. Also, parents indicated that the most helpful support system was family and friends.

Satisfaction with Available Services and Information

Most of the families were satisfied with the Prince George Diabetic Clinic and their pediatrician. A sizable proportion were dissatisfied with their family doctor. All of the eight families visiting the BCCH Pediatric Diabetic Unit were satisfied with their services. Additional significant data includes satisfaction with the emergency ward, pediatric ward and the ophthalmologist. And, although 10 parents were satisfied with teacher activities, three were not. Overall, 59% of the parents indicated that the available services met their needs, while 33% stated that their needs were only somewhat met.

In the themes section of the study, more than half of the parents indicated satisfaction with the PG Hospital Diabetic Clinic. A few parents commented positively on the pediatrician, BCCH and summer camp. However, six parents were unhappy with their family doctor, which is not surprising since type 1 diabetes in children is not their specialty. Six parents also expressed a concern with the cost of diabetes medication and supplies, which are crucial to the child's welfare. Five parents voiced concerns regarding knowledge and approaches to diabetes in school and daycare. Parents felt there should be more diabetes education in school and better communication between parents and schools.

Long wait times for appointments were an issue for five parents, particularly for the PG Diabetes Clinic, which is unfortunate because parents need as much assistance as possible to help them cope and manage their child's diabetes. Another common theme was the problem of dealing with teens with diabetes. Parents felt the stress of teenage issues made it more difficult to manage diabetes. This is discussed more fully in the next section.

Limitations

Although the results in this study are fairly significant and reflect the literature, it would have been helpful if the participation rate was more than 27 out of 60. It is hard to speculate why so many did not respond. Perhaps they are content with things the way they are, or do not like to fill out questionnaires, or perhaps the questionnaire was too long. However, the survey did not have any direct reward or penalty to the respondents. Also, this study did not address whether the children in this research had experienced long-term complications. The literature indicates most complications do not affect children.

There is a second limitation due to the nature of survey research and due to the nature of the topic. Social desirability may have affected the return rate, and even created a biased result in terms of who might have returned survey forms. Those parents who have a stronger desire to do everything that is good for their children are also more likely to be willing to participate in a research survey as well. The survey results may be biased by getting more responses from "good" parents. The social desirability factor may have also affected the claims made by parents in their responses. For instance, we know that parents know their children should have their eyes examined regularly. We know that parents claim to have annual eye examinations. We do not know how many parents actually have followed through with the examination.

An issue that has not surfaced in this study, but has been identified briefly in the literature and workshops, is the serious practice of some young teenage girls who decrease their insulin to lose weight. Unfortunately, this practice does cause weight loss but also sets the stage for chronic irreversible complications. Dr. Daniel Metzger, an endocrinologist at the BCCH Diabetes Unit, once said "beware of the young diabetic teenage girl who is thin" (personal communication). Generally, young teenage girls with controlled diabetes have a tendency to be slightly on the heavy side. There is little information in the literature regarding this problem and it warrants further research.

Recommendations

A number of issues have come forth from the data that need to be addressed or commented on. Only a few parents indicated concern with their schools' approach to their situations. However, the existing level of dissatisfaction is still a cause for concern, particularly in emergency situation. If schools have an inadequate approach to children with diabetes, parents should be persistent in their efforts to initiate and promote better communication and education for teachers.

Only a few children visited BCCH on a regular basis, but those who do were totally satisfied with the services there. The hospital has a vast team of professionals devoted to diabetes in children and an excellent communication system with parents regarding questions and blood sugar and insulin advice. Although it would be advantageous for all the children in the north to be followed by BCCH, it may not be practical not think it would be practical because of the travel expense that would be required. Further, BCCH follows approximately 900 children, and additional numbers may not be feasible.

There were enough parents dissatisfied with their family doctor to deserve comment. Doctors are generally not experienced in type 1 diabetes in children. It would be highly advisable for the parents involved to either visit the diabetes clinic more often or the pediatrician. However, should the family live in a small community devoid of specialists, they may not have much of a choice, other than regular visits to a larger center.

Another issue worth commenting on was long wait times for the PG Diabetes Clinic. Long wait times for most health service in this province are a reality. However when it comes to children's health, particularly a chronic condition such as diabetes, allowances should be made to provide timely health care. The condition is complex and serious enough to receive prompt health services as required. Perhaps using e-mail, a hot line, or fax could be useful here. BCCH has used this system for years and parents are quite happy with it. The emergency department is always an alternative when other health services are not available.

A major concern, although only affecting a few parents responding is the great expense for diabetic medication and supplies. The fact that some parents reuse needles and go for days without testing because they do not have the money to buy strips is unsafe and deplorable. One solution would be for these medications and supplies to be fully financed by the government, although the insulin pump is likely too expensive and not suitable for everyone.

From a personal perspective, if there ever was a need for a parent support group, it is here, for parents of children of diabetes. As a parent of a child with diabetes, nurse and health educator I can see the value of such a group. Surprising to me, even though many indicated they would attend such a group if it existed, just as many indicated they did not have the time. There have been several attempts at establishing such a group, however, attendance was poor. It would be advantageous to try to determine the reason for lack of success of this support group. One drawback may be that the age of the children ranges from birth to 18 years, and problems and issues change as the child grows older.

Teens, boys and younger girls were the only age group identified as being problematic. Parents indicated that the added stress of teenage issues makes it more difficult to manage diabetes. Major areas of concern include maintaining blood glucose control, emotional reactions, compliance with regime and diet. Also, depression, low self-esteem and eating disorders are more common in the teen with diabetes than the non-diabetic teen. None of these issues are a surprise. The teen with diabetes faces many obstacles and may need help coping with the diabetes. Some teenagers rebel or down-play the importance of their diabetic regime. In some cases counselors, psychologists or psychiatrists may be necessary to help the teen through these troubling times. This study and the literature confirm that stress is a common problem for both the teen and family that needs to be addressed for optimal health for the teen. Unfortunately, if teens do not keep their blood sugar under control, not only can it cause acute complications, but it can also the onset of serious long term complications. Numerous adult diabetics with serious complications such as blindness and kidney failure attribute this to neglecting their diabetic regime in their teenage years. In the study, some parents indicated they would like to see more teaching clinics directed at type 1 diabetes and teens. The literature is very clear in that problems not previously present are now making their appearance necessitate increased frequency of contact with the multidisciplinary team.

Summary

It is imperative that all children with type 1 diabetes be followed carefully and have their blood sugars maintained in an acceptable range, in order to live healthy lives with as few complications as possible. The stress and frustration experienced by some families is evident both in this study and the previous research. The initial and ongoing assistance and support of the health care team must be sustained to help these families.

Overall, most parents indicated they used the PGDC and their pediatrician and are satisfied with these services, although wait times are a source of dissatisfaction. Family doctors and schools are not seen to possess the awareness or skills necessary to deal with situations that arise. Issues of need for financial help with diabetes supplies, and support for dealing with behaviour and emotional issues of children, particularly teenagers were commonly mentioned. Yet, expressed desires for support groups, youth camps or other services were mixed. These findings may be affected by selection bias and social desirability effects, common problems with survey research.

REFERENCES

American Diabetes Association. (2003). Care of children with diabetes in the school and day care setting. *Diabetes Care, 26* (Supplement 1) 131-135.

Baine, S., Rosenbaum, P., & King, S. (1995). Chronic childhood illnesses: what aspects of caregiving do parents value? *Child: care, health and development 21*(5), 291-304.

Canadian Diabetes Association. (2005, February 23). Seriousness of diabetes recognized in budget. Canadian Diabetes Association welcomes new funding for diabetes prevention and management. News release. Available at *www. diabetes.ca/Section-NewsRelease.asp?=ID-114.*

Canadian Diabetes Association. (2004, October 27). Obesity and type 2 diabetes: A weighty issue. Canadian Diabetes Association marks November diabetes awareness month. News release. Available at *www. diabetes.ca/Section-Main/NewsRelease.asp?ID=107.*

Canadian Diabetes Association. (2004, April 20). Canadian Association Association. UBC partner on funding for childhood diabetes research. New release. Available at www. *diabetes.ca/Section-Main/NewsRelease.asp?ID=119.*

Canadian Diabetes Association. (2003, October 17). 2.5 million more Canadians now identified at risk for type 2 diabetes. New diabetes guidelines launched today by Canadian Diabetes Association. News release. Available at www.diabetes.ca/Section-Main/News Releases.asp?ID=83

Canadian Diabetes Association. (2004, October 27). Canadian children and the rise of type 2 diabetes. News release. Available at www.diabetes.ca/Section-Main/News Releases.asp?ID=99.

Canadian Diabetes Association. (2006). Clinical Guidelines 2003. www.diabetes.ca.

Cashin, K. M., and Briars, R. L. (1999). Neonatal diabetes: a case study. *Pediatric Nursing, 25*(3), 271-277.

Day, L. (1997). Eating disorders in young adults. In *Diabetes in the Young Conference,* (Division of Continuing Education), April 3-4, 1997, Vancouver, Canada, University of British Columbia Press, pp. 73-79.

Diabetes Conference (2006). *Our communities managing diabetes.* March 16, 17, 2006. Prince George, B. C.

Diabetes Control and Complications Trial Research Group. (1994). Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin dependent diabetes mellitus: Diabetes and complications trial. *The Journal of Pediatrics, 125*(2), 177-188.

Dunbar, P. (2001). Gestational Diabetes: Special delivery. Canadian Diabetes Association. www.diabetes.ca.

Faulkner, M. (1996). Family responses to children with diabetes and their influence on self-care. *Journal of Pediatric Nursing, 11*(2), 82-93.

Frank, M. (1996). Factors associated with non-compliance with a medical follow-up regime after discharge from a pediatric diabetes clinic. *Canadian Journal of Diabetes Care, 20* (3), 13-20.

Gallo, A. (1990). Family management style in juvenile diabetes: A case illustration. *Journal of Pediatric Nursing 5,(*1), 223-32.

Gestational diabetes: Who is most at risk? (2005, March 30). *The Prince George Citizen Newspaper,* p.25.

Golden, M. P. (1999). Special problems with children and adolescents with diabetes. In C. M. Clark(Editor), *Primary Care, 26(*4), 885-893. Philadelphia, PA: W. B. Saunders.

Grey. M., & Kanner, S. (2000). Care of the child or adolescent with type 1 diabetes. *Nursing Clinics of North America, 35*(1), 1-13.

Grey, M., Lipman, T., Cameron, M., & Thurber, F. (1997). Coping behavior at diagnosis and in adjustment one year later in children with diabetes. *Nursing Research (46)* 6, 312-317.

Hatton, D. (1992). *Parents' perceptions of their experiences of caring for an infant or toddler under three years with insulin dependent diabetes mellitus.* Unpublished master's thesis, University of British Columbia, Vancouver.

Hatton, D., Canam, C., Thorne, S. & Hughes, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing, 22*, 562-568.

Health Canada. (2002, November 14). Health Canada launches diabetes public awareness campaign. Retrieved June 20, 2003 from http://www.hc-sc.gc.ca/english/media/releases/2002_75.htm.

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family responses to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing 11*(5), 315-326.

Kovacs, M., Goldston, D., Obrosky, D., & Bonar, L. (1997). Psychiatric disorders in youths with IDDM: Rates and risk factors. *Diabetes Care 20,(*1), 36-44.

London, M. L., Ladewig, P. W., Ball, W. & Bindler, C. (2003). *Maternal-newborn and child nursing: Family centered care.* Upper Saddle River, NJ: Prentice Hall.

McKendry, J. B. R. (1989). Direct costs of diabetes care: a survey in Ottawa, Ontario. *Canadian Journal of Public Health 80*, 14-18.

Ministry of Health Services (2002). *Chronic Disease Management.*

Mitchell, B. & Beth (1996). The effects of an early intervention strategy in improving the adjustment to diabetes in children. *Canadian Journal of Diabetes Care 20* (3), 21-27.

National Diabetes Task Force (1987). *Status of Diabetes in Canada*, Department of National Health and Welfare, Ottawa.

Sperling, M. A. (Ed.). (2005). Diabetes Mellitus in children. *Pediatric Clinics of North America, 52*(6). 1533-1798.

Statistics Canada (1987). *Health and Social Support*,Ottawa.

Toth, E., Lee, K., Couch, R. & Martin, L. (1997). High incidence of IDDM over 6 years in Edmonton, Alberta, Canada. *Diabetes Care 20,(*3), 311-313.

WHO DIAMOND Project Group. (1990). WHO multinational project for childhood diabetes. *Diabetes Care 13,* (10), 1062-1068.

Wright, M. A. & Appel, S. J. (2007). Inhaled insulin: Breathing new life into diabetes therapy. *Nursing 2007, 37 (*1) 46-48.

APPENDIX 1

LETTERS TO THE PARTICIPANTS

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

May 1, 2001

Dear Parent/Guardian,

I am a parent of a child with diabetes, an instructor in the nursing program at the College of New Caledonia and also a graduate student in the Community Health Masters Program at the University of Northern British Columbia.

I am asking for your help with a questionnaire I am conducting as part of my studies at the university. The main focus of the study is to determine which resources parents of children with diabetes in north central British Columbia are using and whether these resources are meeting their needs. The questionnaire takes approximately forty minutes to complete. **YOUR INPUT IS VERY VALUABLE.**

Your name and address were labeled by the Prince George Regional Hospital Diabetic Clinic and are therefore anonymous and confidential. I do not have access to the master list. Your participation is completely voluntary. The completed questionnaires will be kept by me in a locked filing cabinet and disposed of when the study is complete.

The results of this study will be a compilation of information obtained from all participants. The information obtained will be made available to the Prince George Diabetic Clinic, the local Canadian Diabetes Association and any other interested individuals or groups as well as be used as part of my assignment.

If you have any questions about this study please feel free to contact me or my thesis supervisor Dr. Peter MacMillan at UNBC 250-960-5828. If there are any further concerns you may contact the Office of Research and Graduate Studies at 250-960-5820.

If at all possible, please mail your completed questionnaire by May 21. Your time and input is greatly appreciated.

Sincerely,

Kori Friedrich, R.N., B.Sc.N.
College of New Caledonia
3330 22nd Avenue
Prince George, B.C.
Home (250) 563-4662
Work (250) 562-2131 local 492 friedrich@cnc.bc.ca

June 4, 2001

Dear Parent/Guardian,

Thank-you for your participation in completing my diabetes questionnaire. If you have not had an opportunity to complete it yet, I would greatly appreciate your input, it is invaluable to my UNBC assignment.

If you require another questionnaire, I have left some extras at the PGRH Diabetes Clinic.

Thank-you so much for your participation.

Sincerely,

Kori Friedrich, R.N., B. Sc.N.
College of New Caledonia
3330 22nd Avenue
Prince George, B.C.
Home (250) 563-4662
Work (250) 562-2131 local 492 friedrich@cnc.bc.ca

APPENDIX 2

SURVEY

UTILIZATION OF RESOURCES BY PARENTS OF CHILDREN WITH DIABETES

N/A (not applicable) DK (do not know)

Part A Demographics

1. What gender is your child? Male Female

2. What grade is your child in? K 1 2 3 4 5 6 7
8 9 10 11 12 N/A

3. How old is your child? Years___Months_____

4. Where do you live? Prince George______
Other_____________
How long have you lived there? Years____Months____
If less than 1 year, where did you live before? _______________

5. Does your child have brothers or sisters? Yes No
If yes, what are their genders and ages?
1.______________
2.______________
3.______________
4.______________

6. How many parents are there in your child's family? One Two
Other_____________

7. Your child's mother or guardian N/A or Age___________Years
Education______Years
Occupation__________

8. Your child's father or guardian N/A or Age___________Years
Education ______Years
Occupation__________

9. What is your child's ethnic background? _______________

Part B The History and Current Status of the Child's Diabetes

10. At what age was your child diagnosed with diabetes? Years____Months____

11. Did your child have any kind of flu or infection in the weeks or months before diagnosis? Yes No N/A DK
If yes, how would you describe it?__________________________________
____

12. Was your child ill at the time of diagnosis? Yes No N/A DK
If yes, describe the symptoms he/she had? ______________________________
____

13. What month of the year was your child diagnosed? ______________ DK

14. Did you and your child receive information and teaching at the time of diagnosis?
Yes No DK
If yes, where?____
from whom?____
how much? ____
was it sufficient for your needs?___________________________

15. Do any other family members have diabetes? Yes No DK

If yes, what is/are their relationships to your child? ______________________
____
What kind of diabetes do they have?______________________________
____

16. [illegible] w often do you or your child home blood sugar testing?
_________per day or
_________per week
_________don't know

17. How many insulin injections does your child receive per day? ______________

18. W[illegible] have been done, do you know the results? Yes No

19. Which family member(s) [illegible] mostly involved in the daily management of your child's diabetes?
Mother_________
Father_________
Other__________

20. Do you receive any tax benefits because of your child's diabetes? Yes No

21. Is the diabetes [illegible] financial burden? Yes No

22. Does your child wear a medic alert? Yes No

23. Do you experience a sense of frustration when managing your child's diabetes?
No
Yes, occasionally
Yes, frequently

If yes, what aspects of management are most difficult for you?__________________
____
____
____

24. Of the following issues, HBGM, injections, maintaining control, diet, activity/exercise, compliance with the regime, emotional/psychological reactions (or other issues) which were or are particularly difficult during the following periods?
    a. Infancy or preschool____

    ____

    b. School years prior to adolescence________________________________

    ____

    c. Adolescence____

    ____

Part C Utilization and seeking of services and information

25. How often do you use the following services for **direct care** for your child's diabetes?

	never	**yearly**	**2-3 times per year**	**every 2-3 months**	**monthly**
Prince George Diabetes Clinic	1	2	3	4	5
B. C. Children's Hospital Diabetes Unit(BCCH)	1	2	3	4	5
Local Pediatrician	1	2	3	4	5
Family doctor	1	2	3	4	5
Hospital Emergency Department	1	2	3	4	5
Hospital Pediatric Ward	1	2	3	4	5
Public Health Unit	1	2	3	4	5
Counselor	1	2	3	4	5
Psychologist	1	2	3	4	5
Ophthalmologist	1	2	3	4	5
911	1	2	3	4	5
Social Services	1	2	3	4	5
Other ____________________	1	2	3	4	5
____________________	1	2	3	4	5
____________________	1	2	3	4	5

26. How often do you use the following services for **information** for your child's diabetes?

	never	**yearly**	**2-3 times per year**	**every 2-3months**	**monthly**
Prince George Diabetes Clinic	1	2	3	4	5
B. C. Children's Hospital Diabetes Unit	1	2	3	4	5
Local Pediatrician	1	2	3	4	5
Family Doctor	1	2	3	4	5
Pharmacist	1	2	3	4	5
Library	1	2	3	4	5
Internet	1	2	3	4	5
Dietician hot line	1	2	3	4	5
Conferences	1	2	3	4	5
Magazines, journals	1	2	3	4	5
Canadian Diabetes Association (CDA)	1	2	3	4	5
Social Worker	1	2	3	4	5
School Nurse	1	2	3	4	5
Public Health Unit	1	2	3	4	5
Hospital Emergency Unit	1	2	3	4	5
Other ________________________	1	2	3	4	5
________________________	1	2	3	4	5
________________________	1	2	3	4	5

27. Who is the main professional who looks after your child's diabetes?________________

28. Have you had to wait for health care services for your child's diabetes? Yes No N/A DK
If yes, for what service(s)?____
____
How long did you wait for each service?____
____

29. What service(s) do you or would you use in the case of an emergency?
____

30. Does your child's school have special arrangements to provide emergency care if needed?
Yes No N/A DK

31. Are you satisfied with the care your child receives in school? Yes No N/A DK
If no, what kinds of problems or concerns do you have? ______________________
____
____

32. Has your child ever been denied participation in events or activities of any kind because of
his/her diabetes at school? Yes No N/A DK
in the community? Yes No N/A DK

33. Do you need daycare or afterschool care for your child? Yes No N/A DK
If yes, are you satisfied with the care? Yes No N/A DK
If no, what kind of problems do you have?____
____

34. Are you a member of the CDA? Yes No N/A DK
If yes, do you or someone in your family attend the CDA meetings? Yes No N/A DK
If yes, how many times per year?____
If no, why not?____

35. Does your child go to the Diabetes Camp for 7-16 year olds at Gibson's? Yes No N/A
If no, why not?____

36. If the Activity Group for 8-13 year olds were started up again, would your child take part?
Yes No N/A
If no, why not?____

37. If the Parents of Children with Diabetes Support Group were started up again, would you take part? Yes No

If no, why not?____

38. What support system(s) do you use most often or find most helpful?
Family_____ Relatives______ Friends______ Others (list)______________________

Part D Satisfaction with available services and information

39. How satisfied are you with the services?

	Very Dissatisfied	Somewhat Dissatisfied	Neutral	Somewhat Satisfied	Very Satisfied	N/A
P. G. Diabetes Clinic	1	2	3	4	5	6
BC Children's Hospital	1	2	3	4	5	6
Pediatrician	1	2	3	4	5	6
Family Doctor	1	2	3	4	5	6
Emergency Department	1	2	3	4	5	6
PGRH Pediatric Ward	1	2	3	4	5	6
Public Health Unit	1	2	3	4	5	6
Counselor	1	2	3	4	5	6
Psychologist	1	2	3	4	5	6
Social Services	1	2	3	4	5	6
School Nurse	1	2	3	4	5	6
Ophthalmologist	1	2	3	4	5	6
911	1	2	3	4	5	6
School/Teacher	1	2	3	4	5	6
Other ________________	1	2	3	4	5	6
________________	1	2	3	4	5	6
________________	1	2	3	4	5	6

40. Do the available services, meet your needs? Yes No Somewhat

41. Please describe which resources/services are most helpful to you and why. Are there any barriers, including problems with services or resources which make it difficult to manage your child's diabetes? Please add any suggestions you have on what services or resources or activities would be most helpful to you to help you to manage your child's diabetes.

Approaches to the Management of Diabetes[1]

Nutrition Therapy

Nutrition plays an important role in the treatment of diabetes. If possible, nutrition counselling should be provided by a dietician with expertise in diabetes management. The diet should include the four food groups, should be individualized, and should consider the treatment regime. Carbohydrates in particular must be balanced with insulin, and low-glycemic-index foods are preferred as they reduce the post-prandial glycemic response. Sucrose is permitted to make up 10% of the total daily energy and artificial sweeteners are safe to use, except for saccharin and cyclamates, which are not recommended during pregnancy. The recommended intake of protein, fats, alcohol, vitamins and minerals are the same as that of the general population. In type 1 diabetics, moderate alcohol consumption in the evening may cause hypoglycaemia the next morning because alcohol decreases hepatic production of glucose. Some type 2 diabetics may return to normoglycemia through weight loss (Sperling, 2005).

Physical Activity

Exercise is important to the person with diabetes as it decreases blood glucose by increasing glucose disposal and insulin sensitivity, therefore, reducing morbidity and mortality in type 1 and type 2 diabetics. However, prior to initiating an activity program, the individual should be assessed for any contraindications. If the person has been inactive, they may have to start with five to ten minutes per day and increase the time gradually. Approximately 80% to 90% of people with type 2 diabetes are overweight (Canadian Diabetes Association, 2006). Weight gain is also associated with intensive insulin therapy. Weight loss may be achieved with lifestyle changes, behaviour therapy,

---

[1] Please note that the material in this appendix are essentially a paraphrase of the CDA Guidelines.

and possibly anti-obesity agents. The reduced weight may improve glycemic control and may reduce the dosage of oral anti-hyperglycemic agents.

Insulin Therapy in Type 1 Diabetes

People with type 1 diabetes must take insulin injections which are chemically identical to human insulin, on a daily basis. Insulin can be administered by syringe, pen or pump. I am personally aware that the insulin pump is the preferred method of administration for intensive therapy, but costs approximately $6000. Insulin regimes vary depending on numerous factors. The individual may initially go through a "honeymoon" period, during which insulin requirements actually decrease, but this is soon followed by progressive beta cell destruction resulting in increased insulin requirements. A preferred insulin regime includes intermediate or long-acting insulin once or twice a day and fast-acting acting insulin for food intake at each meal. Pre-mixed insulins are available, but are not suitable for people with diabetes who have to make frequent modifications to their dosage.

People on insulin must not only be taught how to give themselves insulin, but also how to make adjustments for food intake, physical activity, and sick days, as well as how to do self-monitoring of blood glucose. An important aspect of patient education is the recognition and treatment of insulin induced hypoglycaemia, which can result in confusion, coma or seizures.

It is important for people with diabetes to be aware that while low to moderate activity may lower blood glucose levels during and after the activity, increasing the risk of a hypoglycaemic episode, high intensity exercise may increase blood glucose levels. If blood glucose and ketone levels are high, exercise should not be performed.

Symptoms of hypoglycaemia may include: a) trembling, b) difficulty concentrating, c) palpitations, d) confusion, e) sweating, f) weakness, g) anxiety, h) drowsiness, i) hunger, j) vision changes, k) tiredness, l) difficulty speaking, m) nausea, and n) headache. When the blood glucose level drops to less than 2.8mmol/L, unconsciousness may occur. Treatment with fifteen grams of glucose is usually sufficient. If the patient is at home and unconscious, glucagon can be given subcutaneously or intramuscularly. Also, emergency services should be called. For severe hypoglycaemia, if possible, intravenous glucose should be administered. Once the hypoglycaemia has been treated, a snack consisting of a carbohydrate and protein should be eaten if a regular meal is an hour or more away.

Pharmacological Management in Type 2 Diabetes

Type 2 diabetes is characterized by insulin resistance and progressive beta cell failure. It is often treated with oral anti-hyperglycemic agents or in combination with insulin to obtain better glycemic control. Anti-hyperglycemics are used if glycemic targets are not achieved within two to three months using lifestyle management. An additional agent may need to be added.

Complications of Diabetes

It is estimated that approximately 80% of people with diabetes die due to vascular problems. Medications such as angiotensin converting enzyme and angiotensin 11 receptor antagonists control blood pressure, reducing the risks for cardiovascular disease and nephropathy. Although a variety of antilipid medications are available, weight loss and exercise may help manage dyslipidemia, as well reduce cardiovascular morbidity and mortality in both type 1 and type 2 diabetes.

Hypertension is a particularly serious problem as it can result in death, coronary artery disease, nephropathy, and retinopathy. Therapy should be initiated if the blood pressure exceeds 130/80. Commonly used medications include: angiotensin converting enzyme inhibitors (ACE), beta blockers or thiazide diuretics.

Diabetic nephropathy is a common cause of renal failure and is associated with smoking, hyperlipidemia, and poor control of blood glucose and blood pressure. The disease can progress from microalbuminuria (urine albumin 30 to 300 mg/day) to overt nephropathy (>300 mg/day) to end stage renal disease. Routine screening is important to detect early signs of the disease and initiate therapy. Two commonly used medications are (ACE) inhibitors and angiotensin 11 receptor antagonists (ARBs). Also, intensive glycemic control and blood pressure control will help prevent the progression of the nephropathy.

Neuropathy is a common problem in people with type 1 and type 2 diabetes. It occurs in 50% of diabetics within ten years after diagnosis (Canadian Diabetes Association, 2006). Motor and sensory problems, as well as pain, are common symptoms, and foot ulcers and amputations may occur. Tests for neuropathy include the use of a tuning fork, pinprick sensation, and assessment of distal muscle strength, sensation, and reflexes. Treatment for pain may include: tricyclic antidepressants and non-addictive analgesics.

Foot problems are a major problem for people with diabetes. Even minor foot trauma can result in ulceration, infection, and gangrene, with possible amputation. Foot care education and glycemic control can help prevent problems, and aggressive and prompt treatment can help heal ulcers.

Erectile dysfunction is a common problem in men with diabetes. Approximately 34% to 45% of men are affected (Canadian Diabetes Association, 2006). Certain risk factors, organic causes, and side effects of some medications, all contribute to the problem. Risk factors include: increasing age, duration of diabetes, poor glycemic control, smoking, hypertension, dyslipidemia, and cardiovascular disease. Microvascular and macrovascular disease and neuropathy also contribute to the problem, as do certain medications such as antihypertensives and antidepressants. A new therapy, type 5 phosphodiesterase inhibitor, is very effective and other treatments such as vacuum constriction devices or penile prosthesis may be considered.

Individuals with diabetes and their families should be screened routinely for adjustment problems and psychological issues. Diabetes is a psychologically and behaviourally demanding disease. Self-care and glycemic control may be influenced by numerous factors such as stress, inadequate social and family support, poor coping skills and beliefs regarding how serious or controllable the diabetes is to manage. Depression is twice as common in people with diabetes as in the general population; 15% suffer from major depression which is associated with poor glycemic control and health complications. Anxiety may also be a problem, for example, the person with type 1 diabetes who is fearful of needles and hypoglycaemia. The patient must be involved in decision making regarding care and education. Some interventions which are particularly helpful include psychosocial support, coping skills training, and family behaviour therapy. Antidepressants may be helpful for people with diabetes who experience depression.

APPENDIX 4

DIABETES IN ABORIGINAL PEOPLE IN CANADA AND DIABETES AND PREGNANCY

These two topics, while tangential to the thesis topic of this thesis are of such importance as to be included in this appendix.

Diabetes in Aboriginal People in Canada

Diabetes in aboriginal people fifty years ago was unheard of, yet today it is an epidemic in progress with a prevalence of three to five times higher, depending on region, than that of the general population. Aboriginal people include those of First Nations, Inuit and Metis, however, most available data is of First Nations people. The high rates are occurring in all age groups; there is a younger age of onset, more type 2 diabetes is represented in children, and increased rates of gestational diabetes are occurring. Also, rates are higher for people living on reserves than off reserves. In some on-reserve First Nations communities, one in four individuals who are over the age of 45 years, have diabetes (Health Canada, November 14, 2002). Young people in the general population usually develop type 1 diabetes; however, in First Nations people the majority of cases are type 2 and some are as young as five to eight years of age, with the incidence increasing at a rapid rate. Also, while the prevalence of diabetes is higher in males in the general population, approximately two-thirds of First Nations people diagnosed with diabetes are women; 30% of whom are initially diagnosed during pregnancy (Health Canada, 2002). A recent study indicated that 70% of First Nations women diagnosed with gestational diabetes developed diabetes within three years, while in the general population typical conversion rate ranges between 25% and 60% over a decade or more.

A wide variety of factors are considered to be responsible for the high rates of type 2 diabetes in aboriginal peoples. The "thrifty gene" theory states a genetic susceptibility may be partly responsible, that goes back to aboriginal ancestry when feast and famine cycles led to very efficient storage of energy. Also, replacement of traditional foods with a diet high in saturated fats and simple sugars, as well as a sedentary lifestyle, lead to a rise in the prevalence of obesity and subsequent diabetes.

First Nations peoples have a high prevalence of complications such as heart disease, hypertension, stroke, lower limb amputations, kidney disease, and eye disease. In Manitoba, Canada, it is estimated that between the years 1996 and 2016, there will be a ten-fold increase in cardiovascular disease, a ten-fold increase in lower leg amputations, and a five-fold increase in blindness in aboriginal people.

Treatment may be difficult due to a number of barriers. Medical resources may not be accessible, there may be a loss of traditional diets and lifestyles, and psychosocial issues and substance abuse may also be factors. Ideally, a multidisciplinary team should implement a diabetes program that considers learning styles, local traditions, and culture. In order to reduce the epidemic, primary prevention of type 2 diabetes through lifestyle modifications, such as is given to traditional activities and foods, must be considered.

Diabetes and Pregnancy

Pre-Existing Diabetes and Pregnancy

The care provided by an interdisciplinary diabetes healthcare team prior to conception and during pregnancy can minimize maternal and fetal risks to women with diabetes mellitus. Pregnancy can affect diabetes significantly because physiologic changes of pregnancy can alter insulin requirements. Women with type 1 and type 2 diabetes should strive to attain a preconception glycosylated hemoglobin A1c of 7% to decrease the risk of complications. Optimal glycemic control can reduce the risk of spontaneous abortion, congenital malformations, pre-eclampsia and progression of retinopathy. The risk of giving birth to a child with a major anomaly in the general population is 1% to 2%, for diabetic mothers this increases threefold (London, Ladewig,Ball & Bindler, 2003). For women with type 2 diabetes taking oral antihyperglycemics, which are thought to be teratogenic, these medications should be discontinued and insulin therapy established. Also, frequent self blood glucose monitoring is essential to determine insulin need and attain optimal control.

Assessment of ophthalmologic and kidney function should be performed before conception, during pregnancy and post-partum. Poor glycemic control can cause progression of retinopathy. Also microalbuminuria and overt nephropathy are associated with increased risk of maternal and fetal complications. Therefore glycemic and blood pressure control should be optimized. Antihypertensive medications may have to be changed to ones known to be safe during pregnancy. Diabetic ketoacidosis (DKA) due to high maternal glucose levels must be avoided, since it is a potentially fatal complication for the fetus. DKA may result due to an increase in ketone bodies, decreased gastric motility, and the anti-insulin effects of human placental lactogen (hPL) released by the placenta in the second half of pregnancy (London, Ladewig, Ball & Bindler, 2003). High maternal glucose levels may also result in an infant that is large for gestational age. The fetus uses the glucose and produces high levels of insulin resulting in excessive growth (macrosomia). This situation may also result in impaired glucose tolerance later in childhood. Two to four hours after birth, the infant may develop hypoglycaemia due to the absence of the mother's glucose, yet maintain continued insulin over- production. Also, in the pregnant woman with advanced diabetes, the fetus may develop intra-uterine growth retardation (IUGR) due to vascular changes affecting placental perfusion.

Most women with diabetes go to full term and deliver without problems; however, should complications occur such as fetal distress, worsening of hypertension and IUGR, birth before term and possibly a caesarean section may be necessary. Ultrasound may be done at 18 weeks and 28 weeks to determine gestational age, detect anomalies, and monitor fetal growth. Close monitoring is required throughout the whole pregnancy. Most importantly, a registered dietician should assist with appropriate nutrition therapy, and insulin therapy must be individualized and regularly adapted to the changing needs of the pregnancy.

Gestational Diabetes

Gestational diabetes is diabetes mellitus that has its onset or is first diagnosed in pregnancy. It is the release of the anti-insulin effects of the hormone human placental lactogen (hPL) by the placenta in the second half of pregnancy, along with the growing fetus, that increase a pregnant woman's insulin needs. In Canada, the prevalence is from 3.5% to 3.8% in the non-aboriginal population to 8% to 18.0% in aboriginal populations (Canadian Diabetes Association, 2006). Although most cases of gestational diabetes disappear after childbirth, babies born to these mothers are five times more likely to develop diabetes in adulthood, and 70% of the mothers will end up with Type 2 diabetes. While women may remain asymptomatic or have a mild form of the disease, it may still cause increased risk for perinatal morbidity and mortality. If the woman is treated, it will reduce perinatal morbidity, for example, macrosomia, hypoglycemia, hypocalcemia, hyperbilirubinemia, respiratory distress syndrome, potential long-term obesity, and glucose intolerance. Risks to the mother include the possibility of delivery by caesarean section, increased urinary tract infections, and the development of pregnancy induced high blood pressure.

Although it is recommended that all pregnant women should be screened for gestational diabetes with a blood test between 24 and 28 weeks gestation, women at risk should be screened in the first trimester. Women at risk include (Canadian Diabetes Association, 2006):

- a previous diagnosis of gestational diabetes
- a previous delivery of a macrosomic infant
- being a member of a high risk population (Aboriginal, Hispanic, South Asian, Asian, or African descent)
- being more than 35 years of age
- being obese
- a diagnosis of polycystic ovary syndrome, hirsutism or acanthosis nigricans
- the use of corticosteroids.

Management of gestational diabetes is important in order to minimize the risks to both the mother and fetus. Plasma glucose levels should be: preprandial<5.3 mmol/L; 1 hour postprandial<7.8 mmol/L; 2 hour postprandial <6.7 mmol/L (Dunbar, 2001). Insulin, such as Humalog several times a day, may be required if the above glucose levels cannot be attained through diet and exercise. The frequency of self monitoring of blood glucose will vary depending on whether blood values are in the recommended ranges. Also, urine may have to be tested for ketones, which are detrimental to the fetus, once or twice a week. However, nutrition therapy is the primary treatment of gestational diabetes and, therefore, women should be followed by a dietician to ensure normal blood glucose, appropriate weight gain, and adequate nutritional intake occurs. Physical activity programs should be individualized according to the woman's condition.

Following delivery of the baby, breastfeeding is encouraged, as some studies have shown that breastfed infants have a lower risk of developing diabetes (London, Ladewig, Ball & Bindler, 2003). The mother should be tested for type 2 diabetes six months post-partum and future pregnancies should be planned with the health care team.