Building Connections: The Maestro Project

Evaluation of a Community Resource for Young Adults with Type 1 Diabetes

by

Norma Van Walleghem

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF SCIENCE

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Winnipeg

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ABSTRACT

Young adults with type 1 diabetes (YA) are at risk for acute diabetic complications and for loss of medical surveillance. *Building Connections: The Maestro Project*, established in Aug02 for YA age 18-25y, uses non-medical case management to maintain contact with YA after transfer to adult diabetes services. There are two distinct groups of participants involved in the Maestro Project: 1) those that were directly referred to the project at age 18 years after graduation from pediatric diabetes care, since August 2002 and, 2) those that graduated from pediatric diabetes care prior to the inception of the project and were later referred to the Maestro Project at age 19-25 years.

The objective of the project was to increase the rate of medical follow-up and education of YA with type 1 diabetes in Manitoba, and thus reduce their morbidity and mortality from complications of diabetes. The evaluation study design was a pretest and posttest design. Several different methods of data collection were utilized including database review, audit of clinical diabetes records, participant survey, data abstraction from published manuscripts for national benchmarks, and qualitative analysis of participant statements.

In summary, in the first 2 years of operation, the Maestro Project helped the Delayed group reconnect with medical services and helped the Direct group reduce the first year fall-out rate. However, there was no evidence of improved short term medical outcomes for YA. This suggests that the difficulties observed after transfer may be the result of a combination between specific characteristics of the YA cohort and specific characteristics of service delivery in the adult care systems. The "systems navigator" model is feasible and acceptable to YA with type 1 diabetes in Manitoba.

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INTRODUCTION

It is well known that bridging the cultures of pediatric and adult medicine is a challenge for adolescents and young adults (YA) with type 1 diabetes, their families and the health care providers who care for them. The rate of acute complications such as diabetic ketoacidosis (DKA) with excess morbidity and mortality is high and non-adherence to diabetes care can lead to severe chronic complications before individuals reach the maturity of their late 20's (Savage 1997). The transition phase may be a window of opportunity to shape the behaviour that will help determine the future health of YA with diabetes.

The economic burden of diabetes is large and growing. Modern intensive treatment according to the landmark Diabetes Control and Complications Trial (DCCT), applied to 120,000 people with type 1 diabetes in the United States who met the study eligibility criteria has been predicted to result in a gain of 920,000 years of sight, 691,000 years free from end-stage renal disease, 678,000 years free from lower extremity amputation, and 611,000 years of life at an additional cost of $4.0 billion over the lifetime of the population with an incremental cost per year of life gained of $28,661 (DCCT Research Group 1993).

According to the Canadian Diabetes Association 2003 Clinical Practice Guidelines (CPGs) for the Prevention and Management of Diabetes in Canada, "all children and adolescents with diabetes should have access to an experienced diabetes health care team and specialized care starting at the time of diagnosis. The complex physical, developmental and emotional needs of children and their families require specialized care to ensure the best long term outcome" (CDA 2003, page S84). In Manitoba, the coordinated care, support, education and research services for children and

adolescents have been centralized as a provincial program at Children's Hospital since 1985. Most youth with type 1 diabetes in Manitoba are followed at the Diabetes Education Resource for Children and Adolescents (DER-CA) from diagnosis to age 18 years. According to the 1996 Manitoba Burden of Illness study, 95% of children aged 0-14 years with type 1 diabetes in Manitoba are followed by the DER-CA (Blanchard 1997). In Manitoba, there are 60 to 75 new cases of type 1 diabetes diagnosed each year in this age group (DER-CA Annual Report 2003, 2004, 2005).

The DER-CA team currently consists of two diabetes nurse educators, two dietitians and a social worker; all five are Certified Diabetes Educators. Emergency telephone service is provided 24 hours per day, seven days per week by three pediatric endocrinologists. The team sees youth from three to four times annually and uses a case manager system to ensure coordinated care. Approximately 40-50 youth are transferred annually from the DER-CA to various adult medical clinics in Winnipeg and rural Manitoba. Since 1995, the DER-CA has had a formal transition program for all youth as soon as they reach age 13 years, to prepare them for transfer to adult care. Adolescents are generally seen alone during clinic visits. Social issues such as smoking, drugs, alcohol, driving, sexuality, contraception and preconception counseling are introduced at this time. At age 15 years, the DER-CA team brings in the topics of surveillance and education regarding the potential long-term complications of diabetes. At age 17 years, the DER-CA team begins planning for the formal transfer to adult care and discusses the options available. The DER-CA has developed a resource book and checklist that is used in all stages of this transition process; these are given to the YA during their last visit to the centre. However, there is increasing evidence that this is not enough to ensure a successful transfer to adult care (Whittaker 2004).

There are many different options for diabetes care and education for adults with type 1 diabetes in Manitoba. There are a number of adult endocrinologists in Winnipeg that regularly see YA with type 1 diabetes and there are many general internists throughout Manitoba. Emergency telephone service is provided by the endocrinologists using variable practice policies, but not by general internists. The Diabetes Research Group (DRG) is an endocrinologist-led, clinical research program for diabetes and related complications involving both pediatric and adult participants. The DRG is active in national and international multi-centre trials, and provides ongoing assessment and education to participants in addition to cutting edge research. Both of the tertiary care hospitals in Winnipeg (Health Sciences Centre and St. Boniface General Hospital) have a specialty team of nurses and dietitians that provide comprehensive diabetes education services for adults with type 1, type 2, gestational, and diabetes secondary to another medical condition. Youville Centre is a community-based health resource that also offers this coordinated approach to diabetes self-management education, including onsite access to a mental health professional. Diabetes services are also available at numerous other community-based hospitals and health centres in Winnipeg, although their level of experience and expertise with type 1 diabetes varies. Throughout Manitoba, each Regional Health Authority (RHA) has a regional diabetes program with specialty trained nurses and dietitians to provide care, education and support to adults with all forms of diabetes, although their mandate is primarily complications risk factor assessment and prevention of type 2 diabetes, particularly targeting older adults and people of First Nations heritage (Manitoba Health 2002). Appendices 1 and 2 contain listings of the main adult diabetes services in Winnipeg and Manitoba.

One of the goals of the Manitoba Diabetes Strategy is to have a specialized, integrated program for YA (age 18-25 years) with type 1 diabetes to assist in transition from pediatric to adult care (Manitoba Health 1998). Until this goal could be attained, the WRHA, along with its Child Health Program, initiated and piloted a novel model of surveillance in August 2002 to help facilitate transition for this challenging population. The program is called *Building Connections: The Maestro Project.* The objective of the project is to increase the rate of medical follow-up and education of YA with type 1 diabetes in Manitoba, and thus reduce their morbidity and mortality from complications of diabetes. The Maestro Project is an administrative initiative that has established a continually updated Microsoft Access database of YA aged 18-25 years with type 1 diabetes in Manitoba. It provides a centralized, coordinated, community-based navigation service for the care, education and support of diabetes in Manitoba. The Maestro Project Coordinator (MPC) maintains telephone and email contact with the YA to lend this support and to help identify barriers to accessing appropriate health care services. The MPC does not provide medical advice or diabetes education. The MPC works closely with community based resource centers in both Winnipeg and the RHAs involved in diabetes education to facilitate follow-up and referrals and enhance community linkages for service. The Maestro Project has also initiated several alternate methods of service delivery for YA. These include a comprehensive website (www.maestroproject.com), a newsletter sent to participants and archived every two months on the project website, a casual evening drop-in coffee group, and evening group educational events. These events are designed to encourage socialization with peers, to introduce and facilitate relationships with community diabetes educators, endocrinologists, researchers, and other service providers. The events are an opportunity

for YA to ask questions and receive expert information about diabetes management, pregnancy, research, new technologies and other relevant information in a relaxed, non-threatening, non-medical environment. The Maestro Project, in conjunction with the DER-CA also initiated a Peer Mentorship support network for adolescents with type 1 diabetes (Mentoring Youth for Teens). A small group of Maestro Project participants act as mentors for adolescents in the DER-CA who struggle with diabetes.

There are two distinct groups of participants currently involved in the Maestro Project: 1) those that have been directly referred to the project at age 18 years after graduation from the DER-CA, since August 2002 and, 2) those that graduated from the DER-CA prior to the inception of the project and were later referred to the Maestro Project at age 19-25 years.

The purpose of this study is to do a comprehensive evaluation of the Maestro Project by answering the following questions:

1. Does the use of a systems navigator increase the rate of medical follow-up and education of participants in the first year after contact?
2. Does the use of a systems navigator decrease the incidence of hospital admissions and acute complications in participants in the first year after contact?
3. Does the use of a systems navigator improve the glycemic control of participants, as measured by HbA1c in the first year after contact?
4. What is the frequency of acute and chronic complications in participants at the time of evaluation?
5. What are the perceived barriers to accessing medical care and education in the adult health care system for participants?

6. Is there a perceived need for the services offered by the Maestro Project among participants?
7. What is the participant usage of the Maestro Project?

It is hypothesized that the first group of participants ("Direct Referral") will have a better outcome (higher rates of medical/educational follow-up, less hospitalizations, less complications, better glycemic control and less perceived barriers to care) during the first year after contact with the Maestro Project as compared to the second group that had a "Delayed Referral". However, confounding this may be the level of social maturation of the "Delayed" group; as they are older they may prove to be more ready to engage in regular medical care. It is also hypothesized that all Maestro Project participants will meet or exceed national benchmarks for rate of medical follow-up after transfer to adult diabetes care. This would strengthen the evidence-base for a program to ensure seamless transition from pediatric to adult diabetes care.

REVIEW OF LITERATURE

A search of the literature was undertaken using the key words "type 1 diabetes", "transition", "adolescence", "young adult" and "navigator". They were entered into the MEDLINE (1966-2006) and CINAHL (Cumulative Index of Nursing and Allied Health Literature, 1982-2006) databases as well as into the search engine Google Scholar (September 2006) to find relevant papers. Reference lists of the relevant papers obtained from the database searches were also manually searched.

Transition versus Transfer

Youth with chronic health conditions face two simultaneous transitions: a developmental transition (from childhood to adolescence to adulthood) and a situational transition (from pediatric to adult health care). They may also have a third transition,

from relative health to sickness, depending on the progression of their illness (Whitehouse 1998). Blum (1993) defined transition as "a purposeful, planned movement of a young person from child-centered to adult-oriented health care systems". Ideally, according to Schidlow (1990), the transition process should begin at the day of diagnosis, should be well coordinated, comprehensive and uninterrupted, yet flexible enough to take into account the adolescent's psychological and social development, the complexity of the illness for the family and their readiness to change. It must also slowly shift the decision-making and daily management from the parent to the adolescent-parent unit, and finally to the YA (Blum 1993). Viner (2000) asserted that transition should not occur before the YA is able to independently manage their diabetes without the help of parents and staff, as this skill is unlikely to be taught in an adult clinic. However, often a disorganized "transfer" occurs rather than transition. Transfer is a sudden arbitrary event where the patient changes from pediatric to adult services with referral information only. Common precipitants for transfer without transitioning are reaching the age of 18 years, leaving school, crises such as pregnancy or a suicide attempt or patient refusal to attend pediatric clinics any longer. With unplanned, abrupt transfer, the onus is for the YA to attend the next appointment in the adult care setting. There is a high risk that they will be alienated by the process and drop out of care altogether. In addition, during this transfer, neither the pediatric nor adult services may feel fully responsible for patient care, which may result in miscommunications, contradictory advice and potential mixed messages. If a period of limbo occurs, the YA may opt out of both systems (Viner 1999). According to the 2003 CPGs, "to ensure ongoing and adequate metabolic control, pediatric and adult diabetes care services should collaborate to prepare adolescents and young adults for the transition to adult diabetes care" (CDA 2003, page S88).

Bartsch (1989) attempted to contact teenagers who had dropped out of their pediatric diabetes clinic without being formally transitioned to adult care within five previous years of the study. Thirty-nine youth were reached, who had an average age of 19 years. Sixty two percent did not have a physician referral when they left the clinic. At the time of the study, 10% were not seeing any type of physician, 69% checked their blood glucose twice per day or less, and 28% had had a hospitalization (5 for DKA, 4 for hypoglycemia and 4 for other reasons). This study, although almost 20 years old, highlights the problems that may occur when a planned transition does not occur.

Social Maturation

Transfer from pediatric to adult diabetes care at the arbitrary age of 18 years occurs at a time of many changes in school, family, relationships, employment, religious and political values and personal maturity, all in the context of declining parental influence and involvement. Adolescents and YA with type 1 diabetes face challenges that differ from those of children and older adults with this disease. Teens have a sense of invulnerability and tend to discount risks to their future health and the need for medical care. Not only do they deal with the usual peer pressures to use alcohol, tobacco, and illicit drugs, they also face the day-to-day demands of living with a chronic disease: frequent blood glucose monitoring, carbohydrate counting, adjustment for exercise, multiple daily doses of insulin, and continuous problem solving in the management of hypoglycemia and hyperglycemia. Non-medical challenges include scheduling and attending multiple medical/educational appointments, disclosing and discussing medical needs with others (coaches, school personnel, and friends) and maintaining diabetes supplies (Svoren 2003).

Studies have shown that coping with these demands is problematic for adolescents as manifested by inadequate treatment compliance, poor glycemic control, negative attitudes towards their disease and treatment, and delayed social maturation into adulthood (Wysocki 1992). Dickinson (2004) conducted interviews with ten teenage girls, aged 16 and 17 years in order to gain an understanding of what it means for this group to live with type 1 diabetes. A common theme that emerged was that for these girls, fitting in with their peers was more important than their diabetes management. Although fears about future complications were expressed by all of the girls in the study, most preferred to ignore it and only two stated that this motivated them to take better care of themselves. Wdowik (1997) used focus groups and interviews to identify factors that affected the ability and motivation of college students with diabetes to engage in appropriate self-care behaviors. Many reported testing their blood sugar much less than in high school, eating poorly due to stress or lack of time to buy and prepare food and choosing a social activity even when they knew it might negatively affect their diabetes. In a different study of patients aged 10 to 19 years, practices such as exercise, insulin injection regularity and frequency of eating and blood glucose testing decreased as age increased (Bond 1992). A study by Ramchandani (2000) revealed that 71% of the students with type 1 diabetes attending college away from home surveyed had difficulty managing their diabetes. In these studies, the most commonly reported barriers to diabetes control were scheduling and time management difficulties, stress, lack of parental involvement, peer pressure, drugs and alcohol, fear of hypoglycemia and inadequate finances. A Finnish study by Kokkonen (1994) examined the social outcomes of patients with type 1 diabetes diagnosed before the age of 15 years and at the age of 19-25 years at the time of the study. Compared to a group of randomly selected healthy

controls, the patients with diabetes showed poor social maturation and a more dependent lifestyle with difficulties in separating from parents. The authors concluded that living with type 1 diabetes from childhood can delay social maturation and in order for these patients to achieve normal social development in young adulthood, they and their families require more support than their healthy peers.

These findings are consistent with a ten-year longitudinal study by Jacobson (1997) that followed a cohort of children and adolescents with type 1 diabetes and an age-matched control group until age 19-26 years. The two groups were compared in terms of their friendship patterns, dating and love experiences, and sense of loneliness. The group with type 1 diabetes reported fewer friends overall, and a lower level of trust and intimacy within love relationships which the authors felt could reflect social inhibition, or cautiousness that may have developed as a consequence of having a chronic disease.

Anderson (2004) recently described a new theory of development that subdivides the young adult period into two different phases:

1) An early phase (approximately 18-22 years) called the "early adult transition" where youth are generally leaving their parental homes, starting post-secondary education, beginning to be self-supporting and starting to assert their independence. Levinson (1978) argued that for this age group, balancing rival academic, social and economic responsibilities resulted in diabetes management being less of a priority in their lives. These patients may be very unreceptive to change, and therefore, according to Arnett (2000), it may be unrealistic to expect them to intensify their diabetes management regime or even to successfully transfer to adult diabetes care.

2) The later phase of the young adult period (approximately 23-30 years) has been described as a time when "adult roles" are assumed (Arnett 2000). During this period, there is often a maturing sense of identity, where the person starts making plans for the future, finishes their education, enters into a stable intimate relationship and employment. The person also begins to recognize the importance of achieving optimal glycemic control and may be much more receptive at this point to improve or change their diabetes self-management. For young women in this stage, preparing for pregnancy is often the motivating force to improve control. For both men and women, their "partner" or spouse may be an important catalyst for change in self-care behaviour (Anderson 2004).

Glycemic Control

The DCCT clearly demonstrated that glycemic control (as measured by glycosolated hemoglobin [HbA1c]) is correlated with the development of long-term complications. A total of 1441 patients with type 1 diabetes were randomly assigned to intensive or conventional diabetes management and were followed prospectively for a mean of 6.5 years. Intensive therapy was associated with a 10% reduction in HbA1c as compared with conventional therapy, which reduced the risk for developing retinopathy by 76%, microalbuminuria by 39%, albuminuria by 54% and clinical neuropathy by 60% (DCCT Research Group 1993). According to the 2003 CPGs, HbA1c should be measured approximately every three months to ensure that glycemic goals are achieved. Although glycemic targets must be individualized, therapy in most adults with type 1 diabetes should be targeted to achieve a HbA1c of $\leq$7.0% in order to reduce the risk of microvascular and macrovascular complications (CDA 2003).

It is well recognized that successful treatment of type 1 diabetes is of particular importance during puberty in order to achieve normal growth and sexual maturation and

to reduce the risk of microvascular complications in adult life. However, with the onset of puberty, glycemic control has been shown to deteriorate. In the DCCT, few of the adolescent participants were able to consistently achieve and maintain target HbA1c levels despite intensive management. Mean HbA1c levels in the intensively treated adolescent group were higher than corresponding values in intensively treated adult participants (8.06% vs. 7.12% respectively) (DCCT Research Group 1994). Bryden (2001) also found that mean HbA1c levels peaked in their patients in late adolescence (average 11.1% at 18-19 years of age). Wysocki and colleagues (1992) completed a cross sectional study of health and adjustment among 18-22 year old patients with type 1 diabetes that had all been diagnosed before their sixteenth birthday. The authors found very poor glycemic control; glycohemoglobin concentrations averaged 13.1% + 4.2%, with 76.5% of participants having results over 10%. Thirty one percent of those providing urine samples had microalbuminuria, an early indicator of diabetic renal disease. The participants reported reduced quality of life and well being compared to healthy controls, demonstrated adequate diabetes knowledge yet poor treatment adherence and had fewer and less satisfying social supports. Although participants did report moderate frequency and continuity of contact with a physician, contact with other health professionals, including diabetes educators, was reported much less frequently. The authors concluded that poor adjustment to diabetes in early adolescence persists into the transition to adulthood. A recent study from New Zealand reported on a chart audit of 237 patients with type 1 diabetes under age 26 years (Scott 2004). They found that glycemic control was generally poor for the entire cohort (mean HbA1c 9.17%), despite the use of intensive insulin therapy and carbohydrate counting. Although glycemic control was the worst in the 15-19 year age group (mean HbA1c 9.9%), HbA1c remained

high in the 20-25 year age group (9.2%). Of the patients older than 16 years, microalbuminuria was present in 25 patients. Of the patients with duration of diabetes over 10 years, 25% had retinopathy (5 sight-threatening) and 10% had no documented eye screening.

A 2004 report from University Hospital Aintree, Liverpool, UK assessed the effectiveness of a dedicated clinic for YA with type 1 diabetes in achieving HbA1c levels <7%. This clinic was established in 1991and was staffed by the same diabetes specialist physician, nurse and dietitian during the study period. Between 1991 and 2001, 386 patients with type 1 were treated with a mean age of 28.7 years. Patients were seen in clinic at least twice yearly and were encouraged to use multiple daily dose insulin regimes. Non-attenders were sent at least three further appointments, and if this was unsuccessful, a home visit was made by the specialist nurse to encourage re-attendance and to maintain care. Over 11 years, the mean HbA1c was 9.19%. Only 3.4% of patients achieved an average HbA1c of <7% and 80% of patients had an average HbA1c of >8%. The authors identified barriers to tight glycemic control in the clinic setting including an inability or unwillingness of patients to comply with insulin regimes long-term and a failure to attend clinic regularly. Although the authors were disappointed by the HbA1c levels achieved in their patients, they concluded that "well-organized, structured diabetes clinics have a very important role to play in the screening and early treatment of microvascular complications" (Saunders 2004, page 579). These results confirmed the difficulty of achieving optimal glycemic control in youth and young adults with type 1 diabetes, but also highlighted the importance of keeping them engaged in the health care system.

Systems for Surveillance

The fact that transition is an issue at all is a testament to the new and remarkably successful age in modern medicine. More than 90% of children born today with a chronic or disabling health condition are expected to live more than 20 years (Reiss 2002). Young adults with type 1 diabetes currently form a relatively small proportion of the practice of an adult physician and may not be noted to have different health care needs from an older population of patients, many of whom have type 2 diabetes with established complications. Court (1991) hypothesized that YA attending hospital-based adult diabetes care services feel out of place and resent identification with the elderly and those who are visibly disabled. Young adults may not be seen as a high priority for overbooked doctors as they are "generally healthy".

Eiser (1993) studied patient's perceptions of transferring from a pediatric clinic and found that pediatricians were perceived to emphasize family and social life and school/work progress whereas adult physicians stressed the risk of long term complications, importance of exercise and the need to maintain strict levels of control. Patterson (1999) also reported that teens recognized a difference in practice styles between adult and pediatric care centers. They found adult providers blunter, not as personal, and did not give as much attention to the youth as the pediatric care providers. As well, the youth described that they felt they were becoming "burned out" in managing their condition and when they felt this way, they would seek out help for health problems only when they had to, rather than proactively.

Reiss (2002) conducted focus groups with a broad range of youth and YA with type 1 diabetes, family members and health care providers. Focus group participants spoke about the intensity of relationships in pediatric health care and the difficulty of

terminating the long relationships that had developed with these providers. They spoke of fears that the adult professionals did not know as much about or provide as high a quality of care as had been provided by their pediatric providers. They expressed dissatisfaction with the lack of multiple services and professional expertise in a single setting and as a result, many YA were working creatively to fashion "a patchwork quilt of health care services" from all available sources. There were also concerns about longer waiting time between follow-up visits and lack of outreach by adult provider systems. Family members and YA also reported that professionals often did not respect them as knowledgeable members of the treatment team in the adult health care system. Dovey-Pearce (2005) also used focus groups to describe the opinions of 19 young adults with type 1 diabetes (mean age 19.9 years, range 16-25 years) regarding the provision of adult services available. The key issues that participants identified for inclusion in adult services included staff consistency, easily navigated clinic structures, provision of age-specific information, civility and emotional, social, medical and developmental support.

Problems with Follow-up

The 1998 CPGs recommend that all individuals with diabetes should be followed medically every 2-4 months and more frequently when indicated (Meltzer 1998). Recent data in Manitoba has suggested that YA are not meeting these recommendations for follow-up: only 26% of YA surveyed maintained regular medical follow-up in the first year after transfer to adult care, compared to 53% that met the recommendation while in pediatric care (Whittaker 2004). However, the small sample size of this study warrants cautious interpretation of the results.

Kipps (2002) found high rates of dropout to care in the Oxford Region of the United Kingdom. They reported a high rate of clinic attendance in their patients two

years pre-transfer (94%), but this declined to 57% two years post-transfer. In response to this phenomenon of high drop-out rates after transfer, a study was completed by Scott (2005) in Halifax, NS to answer the following question: why do YA not attend adult Diabetes Education Centres (DECs) and how can adult DECs better meet their needs? The authors found that of the 75 respondents, 90% had attended a pediatric DEC in the past but only 40% were attending adult DECs. During transition, respondents felt "lost in the shuffle" and suggested that more contact was needed between the pediatric and adult DECs prior to transfer. Respondents also reported that adult DECs did not meet their needs; they felt estranged sitting in a room full of older adults and felt intimidated to attend the clinic if they were in poor glycemic control as they perceived a negative reaction. The top reason for not attending an adult DEC was time constraints. According to the authors, YA wanted autonomy and a leadership role in their care. They preferred group education and social support in a "professional but relaxed" atmosphere that was respectful of their ideas and lifestyle. The top three requested educational topics were new research findings, complications and stress management.

These findings are very similar to those found in a 2003 survey completed by the Young Adult Working Group for the WRHA entitled "Identifying Perceived Needs: Young Adults with Type 1 Diabetes Survey Report". Twenty-six YA between the ages of 18-25 years responded to the survey. These YA stated that they would prefer to see their physician and education team in a friendly, relaxed environment instead of a hospital. They would appreciate reminder notices for appointments, have flexible office hours during days, evenings and weekends and affordable parking. They would like to be able to access a diabetes specialist physician regularly and a diabetes education team on an as needed basis. They want less focus on blood sugar levels (and fewer lectures) and

education tailored to their specific needs and lifestyle issues including new research and technologies. In contrast to the group in Nova Scotia, 71% of these Manitoba YA preferred individual education sessions as opposed to group sessions and were not interested in support groups. The challenges to receiving care included the hassles of obtaining referrals to an endocrinologist if they had not been to clinic for over a year, long waiting times to see different care providers and the low availability of certain professionals such as dietitians, necessitating having to pay those in private practice. The generalizability of these survey findings was limited due to the small sample size and self-selective nature of the respondents, but do highlight areas for improvement in the provision of services for this group in Manitoba.

Consequences of No Surveillance

The consequences of poor glycemic control on the acute and chronic complications of diabetes are well documented for this age group. The young adult years are most often when the early signs of chronic complications first arise (Anderson 2004). Despite improvements in the life expectancy of children with type 1 diabetes over recent decades, there is still a significant mortality in childhood compared with the general population (Edge 1999). In Canada, from 1997-2000, there were 134 deaths in persons with diabetes age 20-29 years. The death rate is more than three times as high for this age group with diabetes compared to 20-29 year olds without diabetes (Health Canada 2003).

DKA is the single most common cause of mortality in people with type 1 diabetes under the age of 40, according to a British Diabetic Association cohort study (Laing 1999). In addition to the risk of death, recurrent DKA has a significant impact on the quality of life of both the person with diabetes and their family and may also accelerate

the progression of microvascular complications. It is important to note that after diagnosis, DKA is 100% preventable (Skinner 2002). According to Skinner, assessment of psychosocial risk factors can predict recurrent DKA. Deliberate insulin omission is the most common precipitating factor. Morris (1997) studied insulin omission in adolescents and YA (aged 15-25 years) and found that 28% did not collect sufficient prescribed insulin from their pharmacies to actually follow their treatment regime.

Insulin omission may result from depression, which is 2-3 times more prevalent in people with diabetes, abuse or neglect, "diabetes burn-out", teen rebellion, needle phobia or fears of weight gain/eating disorder. The process of learning to live and cope with a chronic condition may also lead to feelings of resentment and denial and phases of rebellion against diabetes. The frequency of DKA peaks during adolescence, and although it decreases afterwards, some individuals may continue with bouts of recurrent DKA in adulthood (Skinner 2002).

The Standards Committee of the Department of Internal Medicine of the WRHA conducted an audit of the treatment of DKA in adults in 5 hospital facilities within the WRHA for a 2-year period from April 1998 to March 2000. Preliminary results of this audit were made available in September 2003 and showed that 25% of the 247 adults treated for DKA in WRHA adult facilities were between the ages of 18-30 years. There was one death from DKA in a 29 year old during this period (Personal communication, Dr. Beth Salamon, Chairperson, WRHA Internal Medicine Standards Committee).

A study by Edge (1999) was undertaken to examine the causes of death in young people with type 1 diabetes under the age of 20 years in the United Kingdom. For the years 1990-96, the total number of deaths as a direct result of diabetes was 83 and the standardized mortality ratio overall was 2.3. Most deaths (83%) were associated with

DKA. Of particular concern to the investigators was the large number of young people, particularly males, with poorly controlled diabetes who died at home. Nine young people were found dead in bed, and in a further nine cases the location of the body was not specified. The authors noted that reductions in the mortality rate could be achieved by improving the care of young men with poorly controlled diabetes during the transition from childhood to adulthood. A recent database study by Roberts (2004) confirmed this increased risk of death at a young age. Young adults with type 1 diabetes under 30 years of age admitted to hospital had a nine times greater risk than the general population of dying in the subsequent three years, not only from natural causes, but from suicide.

A prospective, longitudinal cohort study by Bryden (2001) examined the clinical and psychological course of diabetes from adolescence to young adulthood. A total of 76 adolescents completed baseline assessments and 65 were reinterviewed as YA aged 20-28 years of age. The outcome for the YA cohort was generally poor; they found excess alcohol consumption and regular smoking, a high mean HbA1c level, a problem of weight gain and a high rate of diabetic complications (25% of males and 38% of females). Several severe adverse events were also seen; one patient died and two became cognitively impaired as a direct consequence of diabetes.

More recently, Bryden (2003) completed another prospective, longitudinal study that looked at clinical and psychological outcomes. A total of 113 men and women aged 17-25 years completed baseline assessments and 87 were reinterviewed as adults aged 28-37 years. This cohort also showed a poor outcome. There were two deaths from diabetic renal failure, two patients had received renal transplants, two were undergoing dialysis, four were registered as disabled due to diabetic complications and ten had two or more admissions for diabetic ketoacidosis. The overall prevalence of serious

complications increased from 3% at baseline to 37% at follow-up and women were more likely than men to have multiple complications. Psychiatric disorders increased from 16% to 28%. Eating disorders were also prevalent in this cohort; 37% of patients, all women, reported a history of insulin omission for the purpose of weight control. These findings were similar to an earlier study by Bryden (1999) that looked at disordered eating, insulin misuse, weight change, and their relationships with glycemic control and diabetic complications in adolescents followed-up over an eight-year period. In this study, the authors concluded that insulin omission for weight control was frequent among females (30% of the women admitted to misusing insulin to control weight, with the average duration of misuse being two years) and may contribute to poor glycemic control and increased risk of complications. These findings are also consistent with a study by Polosky (1994) that found insulin omission to appear most commonly in young women ages 15 to 30 years. These women evidenced significantly worse glycemic control than those who did not omit insulin and had higher rates of retinopathy and neuropathy, diabetes-related hospitalizations and ER visits.

In Sweden, the Diabetes Incidence Study (DISS) has aimed to register all newly diagnosed patients with type 1 diabetes in the age group 15-34 years since 1983. Henricsson (2003) recently completed a follow-up study on diabetic complications in this cohort. Ten years after diagnosis, 39% of the cohort demonstrated retinopathy (33% had mild, 4.8% had moderate nonproliferative diabetic retinopathy and 1.8% had proliferative diabetic retinopathy). Although a 39% prevalence of retinopathy 10 years after diagnosis may be considered high, the authors stressed the fact that most of their patients had only developed microaneurysms during this time period that may disappear in patients who are

able to improve glycemic control. This underscores the need for regular eye exams, preventative care and optimal glycemic control in this vulnerable age group.

Preconception counseling for young women with type 1 diabetes is essential to achieving adequate glycemic control before and during pregnancy (Anderson 2004). A nationwide, prospective multicenter study was undertaken in eight Danish centers treating pregnant women with type 1 diabetes from 1993-1998 (Jensen 2004). The purpose of this study was to compare outcomes in pregnancies affected by type 1 diabetes compared to the general population. The authors found that type 1 diabetic pregnancies resulted in considerably higher rates of severe perinatal complications compared with the general population. Infants of mothers with type 1 diabetes were delivered earlier, and had increased rates of caesarean section, macrosomia, stillbirth, perinatal mortality and congenital malformations than the general population. The authors were disappointed to note that only 34% of women performed daily blood glucose monitoring at conception and nearly one half did not receive preconception counseling. Women who did perform daily blood glucose monitoring had lower HbA1c, which was associated with a reduction in serious adverse outcomes. The authors stressed that glycemic control, self-care and education of women with type 1 diabetes in the child bearing years still need to be improved significantly to improve pregnancy outcomes.

As previously discussed, the landmark DCCT was initiated 20 years ago and involved 1441 individuals with type 1 diabetes (195 of whom were adolescents 13-17 years of age), in a comparison of intensive versus conventional therapy. At the close of the DCCT, all conventional treatment group patients were offered instruction in the use of intensive therapy and those patients in the intensive group were encouraged to continue their present treatment. One third of the subjects that were originally

randomized to the conventional therapy group continued to use 1 or 2 injections per day while the rest had switched to multiple daily injections (MDI) or insulin pump therapy. Ninety percent of the former intensive therapy group continued with their intensive treatment. The DCCT cohort was examined annually for an additional eight years as part of the follow-up Epidemiology of Diabetes Interventions and Complications (EDIC) study. EDIC data on the 175/195 adolescents showed that four years after the completion of the DCCT, HbA1c levels between the two groups had converged to similar levels of 8.3% for the former intensive group and 8.45% for the former conventional group. The significant findings of this study were the persistent differences in outcome between the original two treatment groups. There was an odds reduction of 74% for progression of retinopathy for the former intensive group compared with the former conventional group (DCCT Research Group 2001). There was also an 84% reduction in the adjusted odds ratio for developing albuminuria for the intensive treatment group, showing that the benefits of previous intensive treatment persisted for a significant time period (documented at 4, 7 and 8 years), despite worsening glycemic control (DCCT Research Group 2003). These observations demonstrated that sub-optimal glycemic control during adolescence has a lasting detrimental effect on the development and progression of complications even after better glycemic control is established. This provides reaffirming evidence of the importance of starting intensive treatment as early as possible and supporting the maintenance of good control throughout the adolescent and YA years to provide strong and durable protection from the development and progression of microvascular complications.

Service Delivery

In the literature, there is an overwhelming consensus that strategies to ensure successful transition to adult diabetes care need to be developed. However, there are few data systematically evaluating different forms of transitional care, although this literature is now starting to emerge. The International Society for Pediatric and Adolescent Diabetes Consensus Guidelines 2000 (ISPAD Guidelines 2000) make the following recommendations for ensuring successful transition:

1) Negotiation and liaison between the pediatric and adult services including, when possible, the organization of joint clinics.
2) Decision on the optimal age and stage of development for transition to joint care or transfer to adult care depending on local services and agreements.
3) Preparing the adolescent for transfer in advance, ensuring that there is no hiatus in care at the time of transfer and that the young person is not lost to follow-up care.

Other possible approaches include information brochures and checklists that cover the process of transition as well as diabetes knowledge, a transition coordinator who is responsible for facilitating transition or a shared care model where the patient alternates for a period of time between the pediatric and adult systems (McGill 2002). Tsamasiros (2002) added that it is important for the pediatric care team to initiate the transition process long before the actual transfer date in order to give the adolescent and family enough time to adjust.

A recent study in Germany used a telephone questionnaire and medical records to examine patients' perceptions and to determine their medical follow-up and glycemic control after transfer from pediatric to adult care. One hundred one patients with a mean age of 22.1 years (+/- 2.4 years) were interviewed. The authors reported that after

transfer, 52.5% of patients changed their adult health care provider at least once, clinic attendance significantly decreased, and over half the patients found it to be a negative experience, although their glycemic control did not change. The authors concluded that establishing transition clinics and creating closer cooperation between pediatric and adult specialists is mandatory in Germany (Busse 2006).

Kipps (2002) completed a retrospective study of case records and interviews of patients recently transferred from pediatric diabetes clinics in order to compare four districts in the Oxford region that were all using different transfer methods. The subjects consisted of 229 young people with type 1 diabetes that were diagnosed under the age of 16 during the years 1985-1995, and who were 18 years or older by 1999. The mean age of transfer was 17.9 years but varied from 13.3 to 22.4 years.

District A: Transfer from a pediatric diabetes clinic directly to an adult diabetes clinic.

District B: Transfer from a pediatric diabetes clinic to a young adult clinic held in a diabetes center at a different hospital.

District C: Transfer from a pediatric diabetes clinic to a young adult clinic held in the same hospital. Patients were introduced to the adult physician in the pediatric clinic prior to transition.

District D: Transfer from a pediatric diabetes clinic to a jointly run adolescent clinic held in the same diabetes center prior to transfer to an adult diabetes clinic.

The authors observed high rates of dissatisfaction among young people who transferred directly from a pediatric diabetes clinic to an adult diabetes clinic (district A). There was a gradual but marked decline in clinic attendance from two years pretransfer to two years post transfer, especially in districts A and B. Poor clinic attendance was particularly evident in those with high HbA1c levels pretransfer. The authors concluded

that transfer to a specialized young adult clinic was preferable to a general adult diabetes clinic, but also argued that resources need to be directed towards maintaining compliance and clinic attendance once transfer has been completed.

This point had previously been stressed in a report by Wilson (1999), who described their experience with the Salford Young Person's Clinic for patients with type 1 diabetes between the ages of 16-25 years. The clinic was established in 1987 and although they had initial success with high attendance rates, there was found to be a significant rise in non-attenders; by 1994, 40% of eligible patients were not attending the clinic. Labor-intensive and time-consuming strategies were implemented to find the "missing" patients. The authors highlighted the need for positive, proactive and non-judgmental interventions in order to maintain medical follow-up for this age group.

Orr (1996) reported a prospective cohort study measuring glycemic control in 82 patients transferring to a YA diabetes clinic after transfer from pediatric care. Their primary outcome measure was HbA1c obtained at each visit for up to one year before and after transfer. The authors reported no deterioration in glycemic control after graduation, although for both males and females mean HbA1c levels remained sub-optimal (9.8% and 10.7% respectively). The authors did not discuss the rate of loss to follow-up in this transition clinic.

A recent study at the Children's Hospital at the University of Parma, Italy provides a model for successful transition (Vanelli 2004). Young adults were transitioned from a pediatric to an adult diabetes clinic within the same hospital. The last visit in pediatric care was attended by both the pediatric and adult endocrinologist. The next follow-up visit was arranged by both specialists, the patient and the family for the adult clinic. The pediatric endocrinologist would then attend the first visit in the adult service, delivering

the transition/summary letter to the adult endocrinologist at the same time. It was not until the patient had their first joint follow-up visit in adult care that they were officially transferred from the pediatric system. Patients were assured that the adult endocrinologist involved in their transition would continue to see them at each visit, and patients were also given direct telephone and email access to their new team. The authors reported the results of an eight year retrospective study of 73 adolescents with a mean age of 21 years (+/- 0.95 years) at transition. A telephone interview was conducted to measure patient satisfaction and the impact of the transition procedure. The researchers also collected data on change in HbA1c and clinic attendance after transfer.

Sixty-four YA were interviewed with a mean age of 26.5 +/- 2.6 years. The mean HbA1c one year post transfer was 7.6 +/- 1.1%, and 7.5 +/- 0.9% at the beginning of the study, which was significantly lower than at pre-transfer (8.8 +/- 2.1%, $p<0.0001$). Ninety-four percent of patients were satisfied with their transition, 92% liked meeting the adult endocrinologist prior to being transferred and 100% liked seeing the pediatric endocrinologist during their first visit to adult care. In adult care the rate of clinic attendance ranged between 92 and 100%. This is the first study to show improved clinic attendance, glycemic control and satisfaction after transfer from pediatric to adult care.

Non-Medical Case Management

A two-year prospective, randomized clinical trial conducted by the Joslin Diabetes Center, Harvard Medical School and the Children's Hospital in Boston compared three treatment programs in 299 youth age 7-16 years with type 1 diabetes (Svoren 2003). Treatment consisted of a non-medical intervention using a case manager called a "care ambassador" (CA), with and without supplementation of psycho-educational modules. The modules were designed to monitor and encourage routine

diabetes care visits to reduce short-term adverse outcomes and improve glycemic control. Care ambassadors were college graduates with no formal medical education, trained by the research and medical staff. Youth were randomly assigned to one of three groups:

CA: The primary task of the CA was to monitor patients' clinic attendance and provide telephone/written outreach to families after missed or cancelled appointments. The CA spent approximately 5-10 minutes with each family per medical visit and 10-15 minutes per family between visits for appointment scheduling.

CA+: Intervention as above supplemented with psycho-educational modules addressing key issues pertaining to diabetes care. The CA implemented these modules at each visit with a scripted protocol and patients received 2-3 pages of brief written materials on the module topics to take home. The CA spent more time, approximately 15-30 minutes per family per visit.

Standard Care (SC): Patients/families did not have a CA to assist with appointment scheduling and did not receive telephone/written outreach after missed/cancelled appointments. They did not receive the psycho-educational materials.

The authors found the CA intervention significantly increased the number of medical visits to their clinic. 68% in the CA group and 80% in the CA+ group had >7 visits during the two years of follow-up. Only 34% in the SC group kept regular appointments every 3-4 months. The CA+ group had significantly reduced rates of short-term adverse outcomes compared with the other two groups; 25% fewer total hypoglycemic events and 40% less hospitalizations and emergency department visits. Individuals in the CA+ group with high-risk HbA1c values were three times more likely to improve their glycemic control than the high-risk youth in the comparison groups. The authors concluded that use of non-medical case management was found to be a

significant cost-effective approach to improving outcomes in youth with type 1 diabetes, although they noted that they may have selectively underreported adverse outcomes to a greater extent from patients in the SC group, who had less follow-up.

Investigators at the University of South Florida reported on a six-month telephone-delivered intervention (TDI) program aimed at increasing medical adherence in their patients (Sacco 2004). A pilot was conducted to investigate the program's feasibility, effectiveness at reducing HbA1c levels, and the willingness of patients to participate. Ten patients age 18-50 years with type 1 diabetes were randomly assigned to one of two groups: 1) Routine Care or 2) Routine Care + TDI. The TDI group received structured telephone "coaching" for 15-20 minutes weekly for three months, then biweekly for three additional months. Undergraduate psychology students who had completed the University of South Florida's Diabetes Self-Management Education Program were chosen as coaches as they have a strong background in behavioral science, are oriented towards the "helping professions" and are less costly than nurses. The intervention was designed to provide information and emotional support, monitor adherence, enhance motivation and foster problem-solving skills without offering medical advice. According to the authors, preliminary results of this pilot study demonstrated the program was feasible, cost effective, acceptable to patients and effective in reducing HbA1c levels (1.2% mean reduction in the TDI group vs. 0.8% in the control group), although the small sample size warrants a cautious view of the outcome data. These reports are intriguing examples of the benefits of using non-medical case management to provide support and information for patients.

Some studies have taken this idea one step further by putting diabetes educators into the role of providing additional telephone support. A meta-analysis of six trials

using adult patients with type 1 diabetes also concluded that minimal changes to HbA1c resulted from additional education via telephone (Montori 2004). These studies suggest that using diabetes educators to provide additional telephone support does not result in improved medical outcomes. However, there are no studies that have specifically used this technique during the transition from pediatric to adult diabetes care.

According to Rosen (1995, page 11) "the very best transition efforts occur when the young person, the family, and all of their health care providers are each active participants in an organized transition plan". Rosen notes that this challenges both pediatric and adult health care providers to negotiate differences in philosophy, assumptions, and approach in order to facilitate the transition experience for their mutual patients. He also reaffirms that careful surveillance is required to ensure that patients are not lost completely, as some adolescents and YA have found the transition process an opportune time to drop out of care altogether.

Conclusions

The passage from childhood to adult life is a very challenging time for young people and their families. For youth with type 1 diabetes, this transition is made more difficult as it is accompanied by changes in their health care needs and delivery. There is evidence in the literature that current health care strategies, both in North America and abroad, have been unable to effectively manage transition for many YA in this difficult and vulnerable group, and that their health and well being is suffering as a result. Efforts need to be made to ensure that all YA and their families are well supported during this transition, thus building a strong foundation for their adult life. The concept of a "navigator" has been described in the literature (Burhansstipanov 1998, Lemak 2004). Different models exist, although common functions include assisting patients with accessing and coordinating services, providing emotional support and advocacy. The Maestro project is a unique program designed to lend this support and help YA and families navigate through the often complex adult health care system. There are no reports in the literature describing a comparable navigation service during transition from pediatric to adult diabetes care. It is clear that more research is needed to describe and evaluate the efficacy of different models of transition, such as this initiative.

METHODS

Study Design

The evaluation study design is a pretest and posttest design. Several different methods of data collection were utilized including database review, audit of clinical diabetes records, participant survey, data abstraction from published manuscripts for national benchmarks, and qualitative analysis of participant statements.

Study Population

The Maestro Project is open to all YA with type 1 diabetes between 18 - 25 years of age in Manitoba. However, only participants who are graduates of the DER-CA were included in the evaluation study; participants who were diagnosed with type 1 diabetes after the age of 18 years and/or did not receive their initial diabetes education at the DER-CA were excluded. The study collected data on the following two groups:

1. **Current Participants of the Maestro Project – "Direct Referral"**:

These participants were graduates of the DER-CA between August 2002 and August 2004 and were referred to adult care with the Maestro Project (n= 84).

2. **Current Participants of the Maestro Project – "Delayed Referral"**:

These participants were graduates of the DER-CA from the years January 1995 to July 2002 with birth years 1977–1984 inclusive, and were transferred from the DER-CA to adult care prior to the inception of the Maestro Project. They were referred to the project after August 2002 (n=164).

Data Collection and Analysis

1) Retrospective Database Review

Quantitative Analysis:

The Maestro Project Coordinator (MPC) established a database of all eligible project participants. Using the existing DER-CA patient database, graduates from the years January 1995 to July 2002 were identified and contacted by telephone and letter with an invitation to participate. Permission to access the DER-CA database was granted by the Medical Director as a continuation of service from the DER-CA. Introductory letters were also sent to all adult endocrinologists and Diabetes Education Centers (DECs) to promote the project and explain the referral process. All graduates of the DER-CA after August 2002 were directly referred to the project. The MPC attempted to contact each participant upon referral and then biannually to inquire about the participant's health status and access to care and diabetes services. If contact was not successful, the reasons for this were recorded in the database.

During the first contact, the MPC recorded participant demographic information and completed a baseline assessment of the following variables: date of last visit to a physician and type of physician seen, number of visits to endocrinologists, diabetes educators, psychologists, social workers or mental health workers, optometrists, and date of last dilated eye exam or retinal photography. All information was by participant self-report and was related specifically to the diabetes care and education received in the 12-month period prior to assessment. If there had been no contact with any health professional in the previous 12-month period, the MPC offered to reactivate and facilitate a referral to an adult endocrinologist. The MPC captured the number and types of all referrals in the database. During each subsequent follow-up contact (at 6 month

intervals), the MPC repeated the same questions to record the number of medical and/or educational visits, or adverse events since the previous contact.

Data Analysis:

Between-group comparisons of categorical outcome variables were analyzed by Chi squared tests of association:

a) Medical and educational follow-up in the year prior to contact with the Maestro Project (Direct group vs. Delayed group).

b) Medical and educational follow-up in the year after contact with the Maestro Project (Direct group vs. Delayed group).

c) Medical and educational follow-up when both groups were at similar ages (Delayed group, "before Maestro" vs. Direct group "after transfer").

Pretest and posttest comparisons of categorical outcome variables were also analyzed by Chi squared tests of association:

d) Medical and educational follow-up in the year prior to contact versus in the first year after contact with the Maestro Project (Direct group: pretest vs. posttest, Delayed group: pretest vs. posttest).

Statistical significance was set at $p<0.05$. Sample size estimation was based on published Canadian data for rate of regular follow-up (defined as three or more medical visits per year in the year after transition from pediatric to adult diabetes care). A rate of 54% medical follow-up as reported by Pacaud (1996) served as the benchmark, as this is the highest rate reported nationally. As the Maestro Project is a unique model for transition, it is hypothesized that the rate of medical follow-up will exceed all published Canadian experience. The sample size required to estimate a 54% follow-up rate within $\pm$ 10%, with 95% confidence would be 95 YA per group.

The MPC tracked the following outcomes at the time of initial assessment and during subsequent follow-up contacts: 1) number of pregnancies lasting longer than 12 weeks, 2) number of live births, 3) number of cardiovascular events (myocardial infarction or stroke), 4) number of limb amputations, 5) incidence of end stage renal disease requiring dialysis or kidney transplantation, 6) legal blindness 7) death (including date of death). These outcomes were quantified at the time of evaluation in order to describe the frequency of chronic complications in participants.

The MPC also collected self-reported information regarding acute diabetes complications (DKA and severe hypoglycemia). The incidence rate per 100 patient-years was calculated for each variable. Chi squared tests of association were also conducted to determine if statistical differences existed between each group's incidence rates.

Qualitative Analysis:

During every initial and follow-up contact, after completing the assessment, the MPC specifically probed for further information by asking the following questions: "Is there anything else that I can help you with?" and/or "Do you have any questions for me"? The MPC then recorded any of these anecdotes in the notes section of the database regarding diabetes-related concerns, problems, and stories etc. that were disclosed by participants to illustrate the perceived barriers to accessing medical care and education in the adult health care system. Key themes are presented and described and anonymous examples from the database are used to exemplify the descriptions. These anecdotes were not verbatim, but were summarized and paraphrased.

2) Audit of Clinical Diabetes Records

The proposal for this research study planned for an audit of pediatric and adult diabetes records of Maestro Project participants. This was planned not only to verify

self-reported information and to determine the extent of recall bias, but also to obtain information about the glycemic control of participants. In addition to demographic information (date of birth, gender, age at diagnosis, age at transfer from pediatric care), data on clinic attendance (physician and educator), diabetes related hospital admissions, and HbA1c measurements from the year before and the year after transfer were to be captured. Pediatric diabetes records were to be audited at the DER-CA. Adult diabetes records were to be audited at the Health Sciences Centre, Winnipeg Clinic and St. Boniface General Hospital, all in Winnipeg, Manitoba. Standardized forms developed by the researcher were to be used to record this information (Appendices 3 and 4). Only the Adult Diabetes Record Audit Form was used in the study.

Sample size estimation was based on the outcome measure, HbA1c. A 1% change in HbA1c was considered clinically significant as demonstrated by the DCCT and the associated correlation with the development of long-term complications (DCCT Research Group 1993). A total of 90 participants (45 per group) would be needed to attain a power of 95% to demonstrate a change in HbA1c of 1.0% at a significance level of 0.05, allowing for a drop-out rate of 20%. However, only 19 participants in the Delayed group and 8 participants in the Direct group consented to have their medical records audited. As such, there was an insufficient sample size to have a meaningful comparison for either the categorical or continuous outcome variables. It was decided that only the records of the Delayed group would be audited, in order to gain an unbiased view of what had happened to these participants during the years after their transfer from pediatric care.

3) Self-administered Survey (Appendix 5)

A survey was mailed to all participants. The MPC also sent reminder emails to participants and posted information regarding the survey on the Maestro Project website and in the newsletter in order to increase the response rate. This qualitative survey had three parts:

a) Demographic information: Information regarding each participant's current age, gender, age at diagnosis, level of education, employment status, and living situation was collected.

a) Personal experience: This section examined each participant's experience with the health care system after they were transferred from the DER-CA. It attempted to explore the reasons why participants may have had periods in their life where they were not followed for their diabetes medical care, and if so, what brought them back into the medical/educational system.

b) Experience with the Maestro Project: This section explored whether or not participants of the Maestro Project felt that there is a need for the services offered.

Direct quotes from anonymous participant statements written in the surveys are presented in italics and are used to highlight key themes throughout the results and discussion sections of this study.

4) Published Canadian Experience

Five published Canadian studies (Frank 1996, Frank 2002, Pacaud 1996, Pacaud 2005, Whittaker 2004) were used to benchmark the rate of medical and educational follow-up after transfer from pediatric to adult diabetes care.

ETHICAL CONSIDERATIONS

This study was approved by the University of Manitoba Health Research Ethics Board. Permission to access clinical diabetes records was obtained by the Health Sciences Centre Research Impact Committee, the Winnipeg Clinic Ethics Committee and the St. Boniface General Hospital Research Review Committee.

The investigator is also currently employed as a diabetes dietitian educator at the DER-CA providing diabetes education to pediatric clients. To minimize potential bias, the research methodology did not include direct contact between the investigator and the participants.

All eligible participants of the Maestro Project were sent an information package explaining the study including an informed consent form and a cover letter from the MPC, along with the survey (Appendices 5, 6 and 7). This mailing was sent by the MPC using names and addresses in the Maestro Project database, and included a stamped, addressed envelope for the return of the consent form and survey. The confidentiality of participants was maintained throughout the entire course of the study. Personal health information (name, address, phone numbers, email address, MHSC, PHIN and HSC numbers) were removed from the database by the MPC prior to the investigator gaining access to it. All participants were coded by their Maestro ID#. All contacts and mailings were through the MPC.

There were no direct benefits to the individual to participate in this research. The benefit to participation was the ability to help future YA who are transferred to adult diabetes care. No mental, emotional or physical harm to the participants were anticipated with the study. There were no risks to participants.

RESULTS

1) Retrospective Database Review

At the time of analysis (March 2006), there were **567** names in the Maestro Project database. Two hundred fifty-two were eligible for evaluation (84 in the Direct group and 168 in the Delayed group).

Table 1: Participants of the Maestro Project

ACTIVE PARTICIPANTS:	N
Delayed Group (N=168): **Complete database information, included in analysis.**	**101**
Incomplete database information, not included in analysis.	48
Living outside of MB for the majority of the year, not included in analysis.	15
Deceased	4
Direct Group (N=84): **Complete database information, included in analysis.**	**64**
Incomplete database information, not included in analysis.	20
Diagnosed with type 1 diabetes after the age of 18 years, and/or did not receive pediatric care at DER-CA.	60
Graduated from DER-CA after August 2004	50
INACTIVE PARTICIPANTS:	
Excluded due to a diagnosis of type 2 diabetes, or diabetes secondary to another medical reason.	16
Deceased (both were cystic-fibrosis related)	2
Moved out of MB.	37
Unavailable as the Maestro Project Coordinator was repeatedly unable to reach these participants by telephone or email.	60
< 18 years of age In December 2003, 16-18 year olds were "pre-transitioned" to the project to receive newsletters, take part in events and activities and become familiar with the project prior to formal transfer at age 18 years.	51
>25 years of age	39
TOTAL	**567**

Quantitative Analysis:

The Maestro Project database provided complete follow-up information for 101 Delayed referrals and 64 Direct referrals, which were used for analysis. Pre-post test and between groups comparisons were analyzed by Chi squared tests of association.

Table 2: Medical/Educational Follow-up

	Delayed (n=101)		**Direct** (n=64)	
	Before Maestro	After Maestro	Before Transfer	After Transfer
# visits/year				
Medical:				
0	40.6%	26.7%	4.7%	10.9%
1-2	42.6%	64.4%	35.9%	73.5%
≥3	16.8%	8.9%	59.4%	15.6%
Educator:				
0	74.3%	58.4%	7.8%	46.9%
1-2	21.7%	38.6%	12.5%	40.6%
≥3	4.0%	3.0%	79.7%	12.5%

The database review clearly demonstrated that few participants are meeting the CPGs recommendation for rate of medical follow-up in the adult diabetes system. For the Delayed group, only 16.8% saw an endocrinologist ≥3 times in the year prior to referral to the Maestro Project, and this actually dropped to 8.9% in the year after referral. For the Direct group, 59.4% met the recommendation prior to transfer to adult care, but this dropped dramatically to 15.6% in the year after transfer. Over ten percent of this group dropped out of medical care completely after transfer from pediatric care. In the Delayed group, 26.7% of participants failed to re-connect with medical care despite intervention by the Maestro Project.

Delayed Group vs. Direct Group:

In the year prior to referral to the Maestro Project, the Delayed group had significantly fewer medical and educational visits as compared to the Direct group in their year prior to transfer to adult care (χ^2, $p<0.001$).

In the year after referral to the Maestro Project, the Delayed group continued to have significantly fewer medical and educational visits as compared to the Direct group in their year after transfer to adult care, despite being older and presumably more mature (χ^2, $p<0.05$).

The average age of participants in the Delayed group at the time of referral to the Maestro Project was 21 years. The average age in the Direct group at this time was 18 years. A between groups analysis was done to compare the rates of medical and educational follow-up when these groups were at similar ages. i.e.) How did the Delayed group "Before Maestro" (when participants were approximately age 20 years) compare to the Direct group "After Transfer" (when participants were approximately 19 years)? At this stage of life, participants in the Direct group had significantly more medical visits (χ^2, $p<0.001$) and educational visits (χ^2, $p<0.005$) as compared to the Delayed group.

Delayed Group (pretest vs. posttest):

The Delayed group had significantly more medical visits in the year after referral to the Maestro Project, than in the year before (χ^2, $p<0.001$). However, the number of educational visits did not change significantly.

Direct Group (pretest vs. posttest):

The Direct group had significantly less medical and educational visits in the year after transfer to adult care than in the year before, in their last year in the pediatric system. (χ^2, $p<0.001$).

Table 3: Medical Outcomes

Medical Outcomes	**Delayed Group (n=101)**	**Direct Group (n=64)**
Acute Complications: DKA Severe Hypoglycemia	10 cases (5 individuals) **3.0 cases per 100 patient-years** 8 cases (5 individuals) **2.4 cases per 100 patient-years**	13 cases (7 individuals) **7.9 cases per 100 patient-years** 8 cases (4 individuals) **4.7 cases per 100 patient-years**
Chronic Complications:	Heart failure (1) Legal Blindness (1) Proliferative Diabetic Retinopathy (4) Amputation (1) Deceased (4): 1) 15 year old female, diagnosed at age 11 years. Died from leukemia 3 months after transfer from DER-CA. 2) 25 year old male, diagnosed at age 11 years. Died from an "undiagnosed neurological disorder" 3) 22 year old female, diagnosed at age 13 years. Died from DKA. 4) 21 year old male, diagnosed at age 9 years. Died during surgery from complications related to DKA.	None
Pregnancy >12 weeks	15	4
Live Births	8	4
Percent With No Documented Eye Screening After Referral to Maestro Project	37%	55%

Chi Squared Tests of Association:

No significant differences were found in incidence rate for either DKA or severe hypoglycemia between the Delayed and Direct groups.

Benchmarks for Acute Complications:

The literature reports varying rates of DKA and severe hypoglycemia. A recent study by Rewers and colleagues (2002) at the Barbara Davis Center for Childhood Diabetes reported on a cohort of 1243 patients with type 1 diabetes from infancy to age 19 years. This group was followed prospectively for four years, for a total of 3994 patient-years, using a computerized patient record system. The authors found incidence rates of 8 cases of DKA per 100 patient-years and 19 cases of severe hypoglycemia per 100 patient-years. Although the results of the present study showed similar rates of DKA and much lower rates of severe hypoglycemia, the self-reported nature of acute complications in the present study may not accurately reflect actual outcomes.

Additional Deaths:

There was also a death in a 19 year old male, diagnosed at age 10 years. He was followed sporadically at the DER-CA since shortly after diagnosis. He dropped out of pediatric care at the age of 17 years, despite repeated attempts to be contacted. As such, he was never formally transferred to adult care or the Maestro Project, although he would have been eligible to be a part of the Direct group. He died from DKA one month after the last attempt by the DER-CA to contact him.

Pregnancy Outcomes:

The Delayed Group reported 15 pregnancies >12 weeks, eight live births and two therapeutic abortions (in one individual). The five pregnancy losses included four miscarriages (in three individuals), and one stillbirth with "diabetes related defects." This

represents a rate of pregnancy loss of 38%. One of the live births was complicated by Erb's Palsy. The Direct group reported four pregnancies >12 weeks and four live births.

Table 4: Care Provider Connection Information

Connection Type	Number of Referrals Provided by Maestro Project		Known Number of Connections Actually Made	
	Direct Group	Delayed Group	Direct Group	Delayed Group
Adult endocrinologist	17	27	10 (59%)	16 (59%)
Adult diabetes education team (nurse or dietitian)	15	37	4 (27%)	16 (43%)
Social Worker/Counselor	0	2	0	1 (50%)
Optometrist	3	16	1 (33%)	9 (56%)

How Many Care Provider Connections were Actually Made as a Result of the Maestro Project?

Direct Group: There were 17 referrals given for an adult endocrinologist. Of these, ten participants attended their appointment (59%), three either cancelled or were a no-show (17%), and it is unknown for the remaining four if they attended or not (24%). There were 15 referrals to an adult DEC. Of these, four participants attended their appointment (27%), three either cancelled or were a no-show (20%), and it is unknown for the remaining eight if they attended or not (53%). There were three referrals to optometrists; one participant attended their appointment, and it is unknown if the remaining two attended or not.

Delayed Group: There were 27 referrals given for an adult endocrinologist. Of these, 16 participants attended their appointment (59%), nine either cancelled or were a no-show (33%), and it is unknown for the remaining two if they attended or not (8%). There were 37 referrals to an adult DEC. Of these, 16 participants attended their appointment (43%), 17 either cancelled or were a no-show (46%), and it is unknown for the remaining four if they attended or not (11%). There were 16 referrals to optometrists; nine participants

attended their appointment (56%), two either cancelled or were a no-show (13%), it is unknown if the remaining five attended or not (31%).

2) Audit of Clinical Diabetes Records

Consent forms were returned from 25 participants; six from the Direct group and 19 from the Delayed group (eight from the Health Sciences Centre, four from St. Boniface General Hospital and seven from Winnipeg Clinic). As was previously discussed, only clinical diabetes records of the Delayed group were audited. Despite repeated requests by the researcher, the medical records department at Health Sciences Centre was unable to locate two records. Audits were completed on July 12, 2006, July 16, 2006 and September 5, 2006. The information obtained from each diabetes record was compared to the information found in each participant's corresponding database record to verify the extent of recall bias.

Of the audited charts, there were nine females and eight males, with an average age of 25.7 years (range 22-29 years). The average age at diagnosis of type 1 diabetes was 9.5 years (range 5-15 years). Only 1/17 (5.9%) of participants achieved an average HbA1c of $\leq$7%. The average HbA1c overall was 8.8% (range 7.0-11.4%). Only 2/17 (11.8%) of participants had medical follow-up $\geq$3 times per year after transfer from pediatric care and 3/17 (17.6%) had educational follow-up at least yearly. There were six acute complications (DKA or severe hypoglycemia) found in 4/17 (23.5%) of participants. None of these events were reported to the Maestro Project, which suggests that acute complications are selectively underreported in the Maestro Project database, reflecting recall bias of participants. Retinopathy was present in 4/17 (23.5%) of participants, although the exact stage was vague in each case. There was one individual

case each of microalbuminuria, erectile dysfunction and contractures, and two participants had hypercholesterolemia.

The clinical diabetes records only provided partial information for many participants for the years after transfer to adult care. Seventy-six percent of participants audited (13/17) had large gaps of care in their records, with an average gap lasting 3.8 years. For half of these participants, it was impossible to tell where, if ever, they had received care during these times. For the reminder, there were varied reasons for gaps in their records: one participant had moved away for college; several were followed solely by a family physician; and some participants had received care from different endocrinologists at different institutions. On the Participant Information and Consent form (Appendix 7), participants were asked to check the box identifying where they see their adult endocrinologist. This was apparently taken to mean their "current adult endocrinologist" and consent was therefore given to only access information from the institution specified. However, it was often impossible to verify how many endocrinologists or diabetes educators had been involved with each participant after transfer to pediatric care as there was generally little correspondence between specialists in the medical record. Although the audit of clinical records did provide useful information regarding the glycemic control, acute complications and medical follow-up of participants, it did not provide a complete picture of the care received in the adult diabetes system. The audit also suggests that participants are not disclosing accurate details regarding their medical information to the MPC.

Table 5: Summary of Audit of Clinical Diabetes Records

N	Gender	Current Age (yrs)	Average HbA1c (%)	Medical F/U	Educational F/U	Acute Compli-cations	Chronic Complications
1	F	27	8.0	1-4 x per year	None	No	Retinopathy Microabuminuria
2	M	24	7.0	1-2 x per year	None	No	None
3	M	26	10.0	2 x per year	Once	No	Erectile dysfunction Retinopathy
4	F	25	7.7	1-3 x per year	Twice	No	None
5	F	26	9.9	2-3 x per year	Yearly	DKA Suicidal ideation/ Insulin omission	Retinopathy
6	M	28	7.7	1-2 x per year	Once	Severe hypo DKA	None
7	F	25	7.4	1-2 x per year	Yearly	No	None
8	F	22	10.1	3-4 x per year	Once	No	None
9	M	26	10.8	0-2 x per year	Twice	DKA x2	None
10	F	29	7.8	Weekly while pregnant	Once	No	None
11	M	26	9.0	3-4 x per year	Yearly	No	Contractures Retinopathy
12	M	23	9.0	2 x per year	Once	Severe hypo	Hyper-cholesterolemia
13	F	27	8.0	2-3 x per year	Once	No	None
14	M	27	9.7	1-2 x per year	None	No	Hyper-cholesterolemia
15	M	24	11.4	None for past 4 years	None	No	None
16	F	27	8.8	2 x per year	3 x in 2006	No	None
17	F	25	8.0	2 x per year	None	No	None

3) Self-administered Participant Survey

Fifteen percent (35/233) of participants returned surveys; nine from the Direct group and 26 from the Delayed group. Two of the surveys from the Delayed group were not used. One survey from a 23 year old male was discarded due to inappropriate responses obviously not meant to be taken seriously. One survey was completed by the mother of a participant with Down's Syndrome as well as type 1 diabetes. As this survey expressed the opinions of a parent, not a YA, it was excluded from analysis. Therefore, results from 24 surveys from the Delayed group will be reported here.

Table 6: Survey of Participant Experience with The Maestro Project

A. Demographic Information	**Direct (n = 9)**	**Delayed (n = 24)**
Percent of males	44%	46%
Mean age (years)	20	24
Mean age at diagnosis (years)	9	9
Education:		
Did not complete high school	0	4%
Completed high school only	0	32%
Currently in university or college	78%	14%
Completed university or college	22%	50%
Employment:		
Working part-time	22%	8%
Working full-time	56%	80%
Not employed	0	4%
Full-time Student	22%	8%
Current living situation:		
Parents	67%	45%
Partner/spouse	0	21%
Friend/roommate	33%	13%
Alone	0	17%
Other	0	4%

Table 6 (Continued):

B. Personal Experience	**Direct (n = 9)**	**Delayed (n = 24)**
Referred to adult endocrinologist	100%	92%
Attended appointment within 1st year of referral	100%	86%
Still receiving care from same MD	44%	58%
Referred to adult DEC	67%	58%
Attended appointment within 1st year of referral	100%	71%
Still receiving care from same DEC	50%	40%
Experienced difficulties after transfer from the DER-CA.	33%	42%
No medical care for > 1 year	44%	46%
C. Experience with The Maestro Project		
Feel that there is a need for The Maestro Project	78%	100%
Feel that The Maestro Project was helpful in motivating them to do better with their diabetes management.	44%	71%

A. Demographic Information:

This data is summarized in Table 6. There were similar numbers of males and females in both groups. The participants in the Delayed group were older, with an average age of 24 years (range 21-28 years), versus the Direct group where the average age was 20 years (range 20-21 years). The average age at diagnosis was the same in both groups (nine years). All participants in the Direct group were either in or had completed university, while a third of the Delayed group had only completed high school. A majority of participants in both groups were working full time, while there were more in the Direct group who were either working part time or were full time students, consistent with the different stages of life expected in the two groups. A high percentage of participants in both groups still lived with their parents.

B. Personal Experience:

1) How old were you when you had your last appointment with the Diabetes Education Resource for Children and Adolescents (DER-CA)?

For the participants in the Direct group, 44% (4/9) had their last appointment at the DER-CA at age 17 years, 44% (4/9) at age 18 years and 12% (1/9) at age 19 years. For the Delayed group, 4% (1/24) were transferred from the DER-CA at age 13 years, 8% (2/24) at age 16 years, 38% (9/24) at age 17 years, 46% at age 18 years and 4% (1/24) were unsure of their age at transfer.

2) Were you referred to an adult diabetes doctor?

3) Did you attend an appointment with this doctor within your first year after transfer from the DER-CA?

4) Are you still receiving medical care from this doctor? How often?

100% (9/9) of the Direct group were referred to an adult diabetes doctor and 100% attended an appointment with this doctor within the first year after transfer. 44% (4/9) were still receiving care from this doctor. One participant reported seeing the doctor annually, one saw the doctor every 6 months and two saw the doctor every 3 to 4 months. Of those no longer seeing their doctor (56%, 5/9), the reasons for this were varied. One participant reported not feeling comfortable with him/her, another felt the doctor was "*not very helpful or informative*", one switched to another doctor without giving any reasons why and one missed the appointments and did not reschedule.

For the Delayed group, 92% (22/24) were referred to an adult diabetes doctor and of these, 86% (19/22) attended an appointment with this doctor within the first year after transfer. Reasons for not attending an appointment included: "*They didn't call*", "*I was out of province attending university*" and "*I didn't want to.*" 58% (11/19) were still receiving care from this doctor and all reported seeing them approximately every six

months. 42% (8/19) were no longer seeing the doctor they were initially referred to. One participant switched endocrinologists, one stated that it was too far to travel, three did not like the doctor they were referred to and two preferred to remain with their family physician, rather than accessing specialty care.

5) Were you referred to an adult diabetes education center (nurse, dietitian)?

6) Did you attend an appointment with this education centre within the first year after transfer from the DER-CA?

7) Are you still receiving care from this diabetes education center?

67% (6/9) of the Direct group reported being referred to an adult DEC. Of those receiving referrals, 100% (6/6) attended an appointment within the first year of transfer from the DER-CA, and 50% (3/6) were still receiving care from that DEC. Two participants were attending appointments every 6 to 12 months and one had only been once. Three participants were no longer receiving care at the DEC, one because they felt that they did not connect with the education team, one switched to a new team and one felt "*no real need at this time.*"

58% (14/24) of the Delayed group reported being referred to an adult DEC. Of those receiving referrals, 71% (10/14) attended an appointment within the first year of transfer from the DER-CA, and 40% (4/10) were still receiving care from that DEC. One participant attended appointments every three to six months, while two went only if they had questions or "*if the doctor thinks I should.*" Six participants were no longer receiving care at the DEC; two switched to a different DEC, and the four did not find it beneficial to attend appointments.

"They seem to be not up-to-date with type 1 living styles."

8) Did you experience any difficulties or frustrations with establishing regular follow-up with your new health care providers after transfer from the DER-CA?

33% (3/9) of the Direct group and 42% (10/24) of the Delayed group experienced difficulties or frustrations with establishing regular follow-up with their new health care team after transfer from the DER-CA. Difficulties with scheduling appointments and making time in their busy schedules to attend multiple appointments were cited as the main challenges for both groups. Several participants in the Delayed group also had trouble adjusting to their new doctor or DEC.

"I felt rushed and very uncomfortable with the doctor."

"It was a fairly large adjustment going from a full team to just a doctor."

9) Has there ever been a time when you have gone for more than 1 year without any medical, nursing or dietitian follow-up for your diabetes?

10) What is the longest time period you have ever gone without having any medical, nursing or dietitian follow-up for your diabetes?

11) Was there a signifying factor that made you decide to reconnect with medical care? Please explain:

44% (4/9) of the Direct group and 46% (11/24) of the Delayed group reported that they had had a time when they went for more than a year without any medical follow-up for their diabetes. Three quarters of these participants in the direct group reported going just over a year without medical care, while one went two years. In the Delayed group, 27% (3/11) reported going >1 year without care, 27% >2 years, 18% (2/11) >3 years, and 18% >4 to 5 years. One participant did not respond to this question.

The reasons for going without medical care were similar in both groups. Participants reported missing appointments because of busy schedules and then having difficulty rescheduling due to long waiting times to see the doctor and the need to obtain re-referrals.

"I forgot to go to an appointment and then couldn't reschedule for a long time."

"I lost track of things with the end of high school and starting a new job."

"I didn't know who to see. I had a hard time finding a family doctor and I needed one of them before finding diabetes help."

A common theme was also the feeling that there was no need for medical care.

"The medical follow-up was not helping me at all."

When asked if there was a signifying factor that made them decide to reconnect with medical care, only one participant from the Direct group gave a response. This participant stated that they sought medical care due to concerns with hypoglycemia. For the Delayed group, a fear of chronic complications brought many back into the health care system.

"I knew that I should be going to see the doctor in order to prevent future problems."

"I'm very concerned with my eyesight, kidneys, nervous system and blood pressure. I'm very disappointed with my doctors for not sending me to a diabetic team."

Some participants also seemed to gain some insight into their own responsibility in managing their diabetes.

"I was trying to better myself, take care of myself and do it for me and my family."

C. Experience with the Maestro Project:

1) How did you hear about the Maestro Project?

100% of participants from the Direct group and 8% (2/24) of the Delayed group reported hearing about the Maestro Project from the DER-CA. 92% (22/24) of participants in the Delayed group reported receiving a call or letter from the MPC.

2) **Have you used any of the following services offered by the Maestro Project?**

Table 7: Services Utilized by Participants

Services	Direct Group (%)	Delayed Group (%)
Referral to endocrinologist	44	8
Referral to adult diabetes education team (nurse, dietitian or counselor)	33	21
Information on how to access an eye doctor	0	13
Information regarding prevention of complications and/or required tests	22	8
Information regarding new research opportunities	11	46
Social contact with other young adults with type 1 diabetes – evening social events, coffee club, other organized activities	11	50
Newsletter	44	75
Website	33	38

3) Before the start of the Maestro Project, where did you go for diabetes-related information and/or referrals?

Prior to the start of the Maestro Project, participants in both groups reported getting diabetes-related information from either pediatric or adult endocrinologists or DECs, pharmacists, the internet, family members and "no where".

4) In your opinion, is there a need for the Maestro Project?

78% (7/9) of the Direct group felt that there is a need for the Maestro Project. Several participants felt the project was valuable by answering their questions and helping them access services.

"It is very useful if I would need to find information or was in need of services. I like always knowing this service could be at my disposal."

These participants also liked the peer events and the opportunity to meet others with type 1 diabetes.

"Sometimes people our age don't see things clearly and knowing there are others like you makes you push on. We also have a lot of unanswered questions."

"Good to be informed and see/know of others who share your successes and failures."

One participant did not feel that there was a need for the Maestro Project.

"I do not see a need for a program whose only offer of assistance is boring, useless newsletters. Perhaps if the program followed through with the services such as referrals, it would be beneficial."

One participant declined to answer.

100% of participants in the Delayed Group felt that there is a need for the Maestro Project. They had many of the same reasons:

"It provides reliable, valuable information that fills a large gap in diabetes care."

"It is difficult for anyone who is just starting out on their own to know where to find everything they need (medically speaking) especially in a city where there are few doctors taking new patients."

These participants also appreciated the peer support provided by the project.

"I don't know a lot of people with type 1 diabetes. It's nice to know all the resources available, especially Bean Bags."

"Creates a "diabetes community" - information/teaching in a casual setting."

"It helps young adults not only make connections with health care teams but also with other young adults."

5) Did you find that the Maestro Project was helpful in motivating or encouraging you to do better with your diabetes management?

44% (4/9) of participants in the Direct group felt that the Maestro Project was helpful in motivating or encouraging them to do better with their diabetes management.

"It keeps you on top of things... always in the back of your mind."

"There was always someone calling me to make sure I was taking care of myself and was generally interested."

56% (5/9) of participants in the Direct group felt that the Maestro Project was not helpful in motivating or encouraging them to do better with their diabetes management. Two of these participants had not really used the services offered by the Maestro Project. One participant reported a bad experience with the project although exact details were not specified. *"I found exactly the opposite, the fact that I was told that the project offered many services that in fact aren't in existence, left me frustrated and discouraged. I believe that I would have had less frustration if the project did not exist because I wouldn't have been lied to about the help I would have been given."*

71% (17/24) of participants in the Delayed group felt that the Maestro Project was helpful in motivating or encouraging them to do better with their diabetes management. Several cited the newsletter and peer events as important aspects of the project.

"The social events and newsletters are always encouraging. It's good to talk to other diabetics. The newsletters have info about new products, recipes, research news, etc."

"If it wasn't for the project and its coffee club I may have never gone on the insulin pump. The project has made me interested in research and new product development."

"Hearing about what others are going through and motivating each other to keep on top of diabetes management."

"I feel that motivation ultimately comes from the patient. The project did try to motivate me, but it was still up to me, and it could have gone either way."

One participant checked off both "yes" and "no."

"Yes because I did want to be healthier and a better diabetic. No, because somewhere in between the 12 years of being a diabetic, my mentality... I seemed to not care anymore.

No matter what I've told myself. I'm trying harder now though. Influences in my current life are making me realize what I could be losing."

One participant declined to answer.

21% (5/24) of participants in the Delayed group felt that the Maestro Project was not helpful in motivating or encouraging them to do better with their diabetes management.

"I have always kept my diabetes as well kept as I could. I'm going to have it for the rest of my life so I might as well do it right."

"With being six hours away, it was difficult to become involved in the social and support aspects."

6) If the Maestro Project were discontinued, where would you go for diabetes-related information and/or referrals?

When asked where they would go for diabetes-related information and/or referrals if the Maestro Project were discontinued, 44% (4/9) of the Direct group reported that they didn't know. *"I have no idea! I guess I would have to begin a long journey until I was able to find who and what I needed."* 33% (3/9) stated that they would ask their family physician, adult endocrinologist or adult DEC. One participant reported that they would manage on their own.

42% (10/24) of the Delayed group reported that they would ask their family physician for information or referrals, 33% (8/24) their adult endocrinologist, 29% (7/24) their adult DEC, 17% (4/24) would access information on the internet, and 4% (1/24) each identified a different resource: CDA, DER-CA, friends met through the Maestro Project and "no where."

"Seeing as it could be up to three years to get a family doctor in our neighborhood, I'd probably end up getting my next referral in the emergency room."

7) Please describe in your own words what it is like to be a young adult with diabetes trying to become independent and self-reliant.

A common theme in the Direct group was trying to balance their busy and changing lives with the demands placed on them by having type 1 diabetes.

"It's not easy, can be very challenging at times. People at this age generally aren't thinking about the future, the complications, the risks we take everyday that will affect us down the road. Quite frankly it scares the @#^& out of me."

Some participants had a more positive outlook.

"It is very hard to come to terms with it but once you realize that you can go on and be okay, it gets easier. I keep myself very controlled and that makes me more independent. You just have to realize that your health comes first."

The Delayed group also reported trying to find a sense of balance in their life.

"It's hard sometimes to have good blood sugars when you're busy from work and other aspects of life. I often worry about low blood sugars because I'm on my own."

"Difficult, frustrating at times trying to keep BG levels within target as eating habits, stress level and daily schedules change. Difficult at times educating people in your life about their role in helping you with your diabetes."

Some participants recognized the need for support from others and acknowledged the difficulty of managing their disease on their own.

"It is difficult and rewarding at the same time. You begin to see how important support from family, other diabetics and medical staff really is. There is a need to find people who can relate to what you are going through."

"If you learned the right habits as a kid the transition shouldn't be all that difficult. I had to take control of my health. Having people around me that understand is a great comfort".

"It's not too hard right now because I still have my parents at home. Once I move out on my own it will probably be harder."

Several participants cited financial difficulties as adding to the burden of diabetes.

"The cost of supplies to properly regulate blood sugars can get very expensive for a young adult learning to live on their own, with new bills and things to worry about."

"It can be difficult financially before my pharmacare deductible is paid off, and can be difficult sometimes spending all the time you need to, to care for my diabetes."

"It sucks. It's expensive. It's time consuming."

Several participants expressed concern for their future.

"Growing up is hard enough and diabetes really isn't that hard to live with... if you ignore it. Growing up with type 1 really makes you understand that taking an active role in your diabetes is far more important than just living with it. I finally understand why my dad used to get so mad at me when I wouldn't record my sugar levels. It's more than just the day-to-day, it really is about the future, and staying healthy for it."

"I had a few years of being perfect with diabetes. Taking my BG four times a day, insulin when needed. After that, I somehow stopped caring. It's tough. Having to depend on medication every day of your life. The realization is unbearable at times".

One participant recognized the role that diabetes had playing in shaping their life.

"Hard for me to say because I think it's the diabetes that has made me independent and self-reliant. These have never been a problem for me, but the project would definitely help those who have problems with independence and being self-reliant."

8) Do you have any additional comments?

Direct Group:

"Although I didn't really participate/use the program, it is quite comforting that in the back of my head I know that there is support, someone there."

"I hope the project keeps going, it's really great."

Delayed Group:

"I would love to see the Maestro Project continue for years to come. Even though I was in a different province it helped me a great deal and I know I would have been a much more active participant had I been closer. I also know that it will be a great help for young adults making that transition."

"The Maestro Project is a fantastic resource and I can only hope it is around for many years to come."

"I have been attending the Bean Bags for under 1 year now – and I feel wonderful when I leave – it's hard to explain".

"I love this project and I am very happy it is around"

4) Published Canadian Experience

The results of the present study were compared to published results from other Canadian programs that have also examined how their patients fare after transfer from pediatric care.

Table 8: Published Canadian Experience

Author/City	N	Pediatric transition Program?	% with "regular" medical F/U (Adult Endo)	Definition of "regular" medical F/U	% with no medical F/U	% with ≥1 visit/ year (Adult DEC)	% with problems after transfer
Frank 1996 Toronto	41	No	76% ? GP	≥1 visit/year	24%	N/A	N/A
Frank 2002 Toronto	76	Yes	87%	≥1 visit/year	7%	60%	N/A
Pacaud 1996 Montreal	135	No	54%	≥3 visits/year	13%	30%	33%
Pacaud 2005 Calgary	79	No	26% GP + endo	≥2 visits/year	14%	28%	46%
Whittaker 2004 Winnipeg	19	Yes	95% 26%	≥1 visit/year ≥3 visits/year	5.3%	52.6%	47%
Van Walleghem 2006/Winnipeg	101	Yes (Delayed)	59.4% 16.8%	≥1 visit/year ≥3 visits/year	40.6%	25.7%	42%
Van Walleghem 2006/Winnipeg	64	Yes (Direct)	89.1% 15.6%	≥1 visit/year ≥3 visits/year	10.9%	53.1%	33%

The follow-up information from the Direct group is for the year after transfer from pediatric care, as is the data from all other cities. The follow-up information from the Delayed group is from the year prior to referral to the Maestro Project. Although it is not technically data for the exact year after transfer, it is helpful when comparing their experience after transfer to that seen in other cities.

A study by Frank (1996) found that 24% of 41 graduates from the pediatric diabetes clinic at the Hospital for Sick Children in Toronto, ON were not being followed medically (defined as at least 1 diabetes assessment per year) after transfer. Frank also observed that the YA who defaulted from regular follow-up tended to resurface in the

medical system months or years later with a diabetes-related crisis which otherwise may have been averted. Consequently, a transition program targeting teens, parents and health care professionals was developed and implemented at the Hospital for Sick Children. The program included workshops and other strategies that provided guidance and support to adolescents and families. Seventy-six youth with a mean age of 21 years who took part in this transition program were evaluated. The authors reported a high rate of success; 87% were receiving regular follow-up with an adult endocrinologist and 60% were connected with a diabetes education team (Frank 2002).

In 1996, Pacaud and colleagues surveyed their patients in Montreal, PQ to determine the existence of difficulties after the transfer from pediatric to adult diabetes care. Regular follow-up was defined as three or more medical visits per year. They found that 50% either expressed having challenges or had a delay or loss of regular follow-up during this time. In fact, 13% reported no regular follow-up for their diabetes at the time of the study. Patients gave many reasons for dissatisfaction including lack of time with the physician, lack of coordination between appointments with the multidisciplinary team and laboratory tests, lack of telephone contact for questions or emergencies and lack of new information in educational sessions. Recently, Pacaud and colleagues (2005) reported a descriptive study that is a replication of their 1996 survey, this time undertaken in Calgary, AB. The authors investigated whether the problems described in Montreal would be generalizable to another city that used a different healthcare delivery model for transfer. They confirmed the results found in the earlier report; 52% of respondents expressed difficulties with transfer, had a delay of regular follow-up or were currently without any routine care.

It is not possible to make statistical comparisons between participants in each of these cities. There are many confounding variables including the type (if any) of transition program present in pediatric care and the definition of "regular medical care". Frank (1996) chose to define follow-up as ≥ 1 visit/year, which she explained "was formulated in consultation with health care professionals" and "based on the minimal expectation for acceptable follow-up (page 14)." Pacaud used the definition of ≥3 visits/year in the Montreal study (1996), and ≥2 visits/year in the Calgary study (2005), which she stated was "modified to be consistent with local medical follow-up practices (page 15)". The Winnipeg studies incorporated two of these definitions; ≥1 visits/year is expressed as a means of comparison to Frank and ≥3 visits/year is expressed as a means of comparison to Pacaud.

There are also differences in the type of physician providing follow-up in the adult care system. In Frank's first study (1996), the type of physician seen was not specified, just the "current physician", which may include family practitioners. However, Frank (2002), Pacaud (1996) and Whittaker (2004) did specify the rate of follow-up with an adult endocrinologist. In Pacaud's 2005 study, the rate of follow-up included those patients who had shared care between the endocrinologist and family physician. When designing the current study, it was decided to describe follow-up with specialty care: an adult endocrinologist and DEC. The 2003 CPGs state, "There is evidence that patients with type 1 diabetes who have a higher proportion of care provided by specialists (endocrinologists, diabetes specialists or diabetes clinics) have reduced incidence of diabetes complications" (page S14).

Frank (2004) had similar rates of follow-up as the Direct group in the current study; 87% of Frank's group and 89.1% of the Direct group had ≥1 visit per year with an adult endocrinologist and 60% of Frank's group and 53.1% of the Direct group were

connected to an adult DEC. Both groups exhibited similar rates of drop-out to care: 7% of Frank's group and 10.9% of the Direct group dropped out. Previous studies have reported drop-out rates of 24-69% (Bartsch 1989, Frank 1996, Wilson 1999), which is closer to that observed in the Delayed group (40.6% were lost to follow-up prior to referral to the Maestro Project). After referral, 26.7% failed to re-connect with medical care despite intervention.

Whittaker's 2004 study had a very small sample size (n=19), which may result in selection bias. The study was a chart review that reported 95% of participants saw an adult endocrinologist $\geq$1, and 26.3% saw one $\geq$3 times. Fifty-two percent of these participants were connected to an adult DEC. The drop-out rate was the lowest seen in any city; only 5.3% did not have regular follow-up. However, it is very likely that this was an underestimation, as those who had fallen out of care would be unlikely to agree to the study. Also to note is that it is possible some participants from Whittaker's study may also have met the inclusion criteria for the present study, and thus were part of the Delayed group as well. Whittaker derived her sample from patients at the DER-CA who were transferred to adult care between June 1994 and June 1999. Participants in the Delayed group were graduates of the DER-CA from the years January 1995 to July 2002. Results from the Delayed group and Whittaker's study are very different.

The highest rate of medical follow-up with an adult endocrinologist was seen in Montreal (54% had $\geq$3 visits per year), despite the fact that there was no transition program in place in pediatric care prior to transfer. According to Dr. Pacaud "*The differing practices for follow-up between the provinces reflects differing remuneration patterns between provinces. In Alberta, an endocrinologist who sees a non referred patient for diabetes care and spends 20 minutes with him will be paid close to the same*

amount as a GP seeing a follow-up for otitis for 5 minutes. A full consult cannot be billed more frequently then every 6 months. In Quebec, endocrinologists can bill a specific code for intensive diabetes management which reflects more appropriately the complexity and the time spent with patients with type 1 diabetes. So in Quebec, most individuals with type 1 are followed by endocrinologists. At least this was the case 10 years ago"(Personal communication January 15, 2007). This rate of medical follow-up in Montreal is much higher than that found in the Delayed and Direct groups of the present study (16.8% and 15.6% had ≥3 visits per year respectively). In fact, the Delayed group exhibited the lowest rates of follow-up of any group, in the years before referral to the Maestro Project. High rates of participants expressed difficulty with transition, ranging from 33% in the Direct group and in Montreal, to approximately 45% in all other cities. The problem with transition is widespread across the country, and appears to be somewhat along a continuum; the Direct group seems to be faring better and the Delayed group faring worse, when compared to other centers.

DISCUSSION

This study has confirmed reports in the literature describing the overall poor health of many YA with type 1 diabetes. Participants of the Maestro Project have rates of medical follow-up that are far below that recommended by the CPGs. Many have no routine follow-up with diabetes educators or eye specialists. The Delayed group has poor glycemic control and several participants have already begun to experience serious, chronic complications before their thirtieth birthday. Participants experience acute complications, although no statistical differences were found between the groups. Over 10% of the Direct group continues to drop out of medical care completely despite

intervention by the Maestro Project. Many barriers to care after transfer to adult care were identified by participants.

Across the country, YA with type 1 diabetes struggle with similar problems during transition, despite wide variations in the types of pediatric clinics, transition programs and adult health care systems in place. This suggests that these difficulties may be the result of a mismatch between specific characteristics of the YA cohort studied and specific characteristics of service delivery in adult care systems. Pacaud (1996) postulated that some of the reasons for YA having poor follow-up in the adult system may be explained by a delay in psychosocial maturation. Her participants reflected "a certain lack of self-care independence needed to function well in the actual adult care services" (page 19). Pacaud went on to say that regular follow-up would be resumed when these YA were able to connect with a physician that understood their needs or when the YA resolved their delay in maturation so that regular adult services could meet their needs. This implies that either the YA or the system must change in order to achieve success.

Differences between Pediatric and Adult Diabetes Care

The adult diabetes care system differs in many ways from the pediatric system including philosophy, coordination and integration with diabetes educators, psychosocial expertise and support, and staffing levels. Adult care is often provided by a single doctor, is patient-centered, more investigational and requires autonomous, independent skills on the part of the patient. In the care of adults, health care providers and patients are presumed to share equal responsibility for their care. Adult providers generally speak directly to their patients, with family members and/or significant others as "supporting players" (Rosen 1995). According to Blumer (2005, page 184), "children and families,

accustomed to being cared for by a pediatric health care team, are often ill-prepared for the greater self-reliance and autonomy that adult-care physicians typically expect of their patients." Care in the adult system is strongly based on patient empowerment; recognizing that the person with diabetes is completely responsible for the self-management of their disease. As such, patients make informed decisions about their self-management, have complete control over these choices and therefore must deal with any resulting consequences. According to Anderson (2000, page 20), "although we can not relieve our patients of this responsibility, we can teach them the skills and supply them with resources to help them carry out this responsibility."

Pediatric care is most often multidisciplinary, family-centered and requires parental consent (McGill 2002). Pediatricians are trained to observe, assess, chart and facilitate growth and development throughout childhood. However, the expectation for adult care providers, for most of their patients, is progressive decline rather than growth (Rosen 1995). Decisions are made by the pediatric provider and parents on the child's behalf, a relationship that must evolve as children become adolescents and begin to take on more responsibility for their diabetes. According to Viner (1999, page 271) "adolescents sit poorly between the family-centered, developmentally focused, pediatric paradigm (which frequently ignores their growing independence and increasingly adult behavior) and the adult medical culture, which acknowledges patient autonomy, reproduction and employment issues but neglects growth, development and family concerns". As such, services for adolescents and YA "need to strike a delicate balance between being respectful and encouraging of youth taking responsibility for their treatment and service choices, while recognizing and addressing the limitations of their knowledge and skills" (Davis 2003, page 502).

Characteristics of the Adolescent/Young Adult Cohort

The transition to adulthood can be difficult for any YA. Over the last twenty years, one of the national trends for Canadian YA is their growing tendency to remain in (or return to) the parental home. The Census showed that 41% of the 3.8 million YA aged 20 to 29 years still lived at home with their parents (Statistics Canada 2001). The survey in the current study found that 67% of the Direct group and 45% of the Delayed group were still living with their parents. For families in this transitional time of life, a fine balance between encouraging self-sufficiency and providing a "safety-net" is required. Some YA are still very dependent on their parents, some are completely independent, and many go back and forth between the two extremes (Davis 2003).

It is unrealistic to assume that a complete transfer of diabetes responsibility from parents to YA will occur by the age of 18 years, especially if there were struggles with the diabetes in adolescence. Often, the problems observed after transfer to adult care are present while the youth is still in pediatric care. Local experience verifies reports in the literature suggesting that adolescence is often a time of worsening glycemic control. According to the DER-CA Annual Report 2005, there is a marked age gradient for HbA1c, with a mean of 9.0% in those aged 15-18 years. In 2003, the youth at highest risk with HbA1c $\geq$ 12% were all exclusively adolescents (DER-CA Annual Report 2003). Confounding this problem, is that if these high risk youth did not regularly attend appointments in the pediatric system they will have missed much of the "transition education" and as a result are even more ill prepared to manage on their own in the adult system. There were several examples of this phenomenon in the database: a 19 year old female had four episodes of DKA in pediatric care and two more immediately after transfer; an 18 year old male with sporadic follow-up and five episodes of DKA in

pediatric care had three more episodes of DKA in the first year after transfer. A recent Canadian editorial suggests that some adolescents would benefit from an earlier transfer to adult care, rather than waiting for the arbitrary age of 18 years. "Many a teenager, uncomfortably sitting in a waiting room full of grade-schoolers, stops attending pediatric programs before transition has been organized and end up attending neither pediatric nor adult care (Blumer 2005)." Identifying these adolescents earlier and helping to organize their transfer to adult care may be a viable option, before they drop out of pediatric care completely.

The current study also confirms that parents struggle during transition with relinquishing responsibility of diabetes management. It is DER-CA policy that adolescents are generally seen alone after age 15 years. Some parents in the Direct group reported feeling in the dark about the transition plan and as such, used the Maestro Project as a support system of their own. Some parents have asked the MPC to try to "talk some sense" into their YA. For example, one father of an 18 year old male contacted the MPC after his son had DKA three times in the year after transfer from the DER-CA. His son would not seek medical care and his father did not know what to do for him. One mother of a 19 year old female contacted the MPC for information about preconception counseling rather than the participant enquiring herself. It is apparent that many YA have not taken on adult roles although they have reached the age of "adulthood".

"It's hard enough growing up these days and add diabetes to that, and unfortunately diabetes suffers. It's a lot easier for a teen-young adult to see the right people when someone tells us where to find them."

"Hard to stay focused on your health when so many other important factors in life such as making money to live. Easy to let things "slip" and then they become bad habits."

This study verifies many previously published reports that have suggested a delay in psychosocial maturation among YA with type 1 diabetes that may have developed as a consequence of living with a chronic disease (Jacobson 1997, Kokkonen 1994, Wdowik 1997, Wysocki 1992). Some participants are also struggling with depression, drinking and drugs, which interferes with their ability to take care of their diabetes and manage multiple appointments.

"For a person without diabetes, trying to become independent, move out on your own, go to university etc. can be difficult and stressful. Unfortunately, with diabetes, I tend to put my health and blood sugars second and focus on all my new challenges, which then makes my diabetes worse and adds to the stress"

Understanding the unique needs of this group is essential to providing appropriate services in the adult health care system. As Whittaker (2004, page 11) summarized "the healthcare system must also work to better understand, accept and integrate the often conflicting wishes of the young adult for independence, who at the same time, expresses difficulty booking and attending appointments". This was a common theme for not maintaining medical care in the current study. Even when participants were specifically given a referral to an adult endocrinologist or names and contact information for a DEC or optometrist by the MPC, many YA still did not make or attend the appointment. Less than half of these potential connections were actually made (Table 4, page 48), which reflects a lack of maturity in participants that is needed to follow through with their care. It is also possible that some participants may have been just "humoring" the MPC; accepting the referral to get her "off their back" with no intention of actually making or

attending the appointment. For example, a 26 year old female from the Delayed group had not seen an endocrinologist for over three years before being contacted by the MPC. She was initially referred to an adult endocrinologist, and then received additional referrals to two others as well as a DEC, yet repeatedly was a no-show to all appointments without explanation. A 24 year old male, also from the Delayed group was transferred from the DER-CA in July 2001. The MPC made a first contact with him in December 2002. He had not had any medical care since transfer as he was under the impression that "everything stopped" when he turned 18. He did not realize that he had been transferred to an adult endocrinologist and DEC. He was given new referrals to each; he was a no-show to the DEC and did not bother to make the appointment with the endocrinologist. He later reported to the MPC that he was unconcerned. "*Everything is fine, the less I think about complications the less likely they are to happen.*"

Denial regarding the possibility of getting chronic complications was also a recurring theme. Although many participants expressed worry about complications, for some, it was not a motivating factor for improving their self management. For example, a 25 year old male from the Delayed group had not had any medical care for ten years before being contacted by the MPC. He had seen an optometrist in the past and was told he had "some hemorrhaging." Despite reporting to the MPC that his vision was not as good as it was before, he refused to do anything about it. He received referrals from the MPC to an adult endocrinologist, DEC and optometrist, but the MPC was never successful in contacting him again.

A 24 year old male from the Delayed group had not seen his endocrinologist for more than two years. He knew that he needed a new prescription for his renal medication, but the doctor would not re-prescribe without a follow-up appointment. This participant

informed the MPC that he would not make the appointment to see the endocrinologist because his blood sugars were out of control and he "*didn't want a lecture*".

However, many participants in the Delayed group became more receptive to assistance by the Maestro Project and adult diabetes care as they got older. There were numerous examples of this observed in the current study. A 29 year male was contacted routinely by the MPC starting in September 2002, although he did not participate in the project for the first few years. He re-initiated contact by himself in 2005 as he wanted to get serious about taking care of his health. He was working long hours doing manual labor and his older sister (also with type 1 diabetes) was having some difficulties with complications after her three pregnancies. He had several appointments with an adult endocrinologist, DEC and optometrist, started more intensive diabetes management, had laser surgery on one eye, and started a new medication for renal protection. A 27 year old female had not seen a doctor routinely after transfer from the DER-CA. She was referred to an adult endocrinologist but did not like him/her – "*just got a bad vibe.*" She finally contacted the MPC when she wanted to get pregnant and was referred to a new endocrinologist and DEC for preconception counseling. A 26 year old female did not receive regular medical follow-up for the first nine years after transfer from the DER-CA. After one miscarriage and one stillbirth, she was ready to intensify her diabetes management and continue to try to have a family. She was referred by the MPC to an adult endocrinologist and DEC and resumed regular medical care. A different 26 year old female from the Delayed group did not see an endocrinologist or educator for ten years. She was brought back into the medical system when her young son was diagnosed with type 1 diabetes and she realized that she needed to start to take care of herself for her son's sake. A 24 year old woman contacted the MPC after a "*reality check*" at an

optometrist appointment. She hadn't had any medical follow-up for over two years and wanted to reconnect and intensify management. She received referrals for an adult endocrinologist and DEC, and had two surgeries for proliferative retinopathy.

"I grew up. I finally realized that if I just ignored it no one would take care of it for me, so I realized that it was my responsibility."

These are examples that demonstrated how many participants of the Maestro Project were able to use the project services to find success in the adult diabetes system, once they were mature enough to take an active role in their health care.

Perceived Barriers to Care

The fact that many YA with type 1 diabetes struggle with accessing and receiving services after transfer suggests that barriers exist for them in the adult diabetes care system. The Canadian Council of Health Services Accreditation uses a specific definition of quality to serve as the basis for all aspects of accreditation for health care organizations. Eight quality dimensions are used to measure the performance of a health system: population focus, accessibility, client-centered services, continuity of services, effectiveness, efficiency, safety and work life. (Personal Communication, Dr. Michael Moffatt, Executive Director, Research, Quality & Decision Support, WRHA). Five applicable quality dimensions will be discussed as a way of identifying barriers to care perceived by participants of the Maestro Project.

1) Population Focus: "Current and future needs and expectations of clients, community populations, and changes in the environment are anticipated and responded to collaboratively."

In 1998, *Diabetes* A Manitoba Strategy stated under Goal 8 (Care): "A specialized, integrated care program for young adults (age 18-25 years) with type 1

diabetes would assist in transition from pediatric to adult care" (Manitoba Health 1998, page 28). Now, almost ten years later, the government of Manitoba is still a long way away from fulfilling this goal. Since its inception, the Maestro Project has been largely funded by community grants from the Lawson Foundation, Canadian Diabetes Association, Manitoba Institute of Child Health, Children's Hospital Foundation of Manitoba and Manitoba Medical Services Foundation. To date, planning for long-term sustainability of the Maestro Project is ongoing within the WRHA, although no permanent funding has been secured.

One challenge with the medical system is that individuals with type 1 diabetes account for less than 10% of all persons with diabetes in Canada (Manitoba Health 1998). The looming epidemic of type 2 diabetes not only locally, but worldwide has overshadowed the needs of this relatively small and stable population. "In 2000, the World Health Organization (WHO) estimated that over 177 million people will have (type 2) diabetes. By 2025, this figure will top 300 million" (Canadian Diabetes Association website, accessed November 9, 2006 at www.diabetes.ca). Subsequently, the population focus has shifted to type 2 diabetes prevention.

2) Accessibility: "Required services are easily obtained by clients and the community in the most appropriate setting."

In the pediatric diabetes care system, patients have a single appointment every three to four months, where they have their blood work done (including HbA1c with results available in six minutes), see their endocrinologist and a diabetes educator, all in the same clinic location, on the same day. To meet the CPGs to ensure glycemic targets are being met or maintained, it requires the patient to have in general, three to four appointments per year or more if indicated. In the adult diabetes system, the patient must

get their blood work done one to two weeks before their endocrinologist appointment and then usually make a separate appointment with a diabetes educator, often in a different location. This could translate into 9-12 separate appointments per year in the adult system in order to receive the same services as they did in pediatrics. Participants of the Maestro Project have overwhelmingly expressed the view that it is impossible to accommodate this schedule of follow-up into their busy lives. For example, a 22 year old male in the Delayed group routinely cancelled his endocrinologist appointments because he couldn't find time to get his blood work done ahead of time, and he felt that it was not productive to go to the appointment without having his HbA1c done first.

Several participants complained that it was difficult to actually see their adult endocrinologist as the office frequently cancelled/rescheduled their appointments. A 20 year old male reported that "*they kept moving my appointments and not telling me – I'd show up and be told the appointment was cancelled – it happened four times*". He then went to rebook and was told he would need a new referral before being allowed to make another appointment to see the doctor. This need for referrals is perceived by participants to be a large obstacle in the adult system; the endocrinologist's office is not bound to honor a referral if 12 months time has lapsed between appointments.

"I had not seen (adult team) *for several years because there was no need and I had to get a referral back to them. It was obvious I needed to speak to somebody about a concern and was still a diabetic. Why was a referral necessary? Seems like a waste of time. Went to* (a different team) *instead."*

3) Client-centered Services: "Care and services are respectful and responsive to needs, preferences, culture and values of individuals, families and communities".

Many participants commented on the difference in "atmosphere" of the clinics in the adult system. Adult endocrine clinics have a very wide age range of individuals attending, and although some have type 1 diabetes, many of the patients have type 2 diabetes or other non-diabetes endocrine concerns. As a result, they did not feel like they could relate to others in the waiting room in the same way that they could when attending pediatric appointments, where all the other patients had type 1 diabetes. Some participants felt that the Maestro Project had a role in providing this sense of community and belonging that they felt they were missing in the adult diabetes system. (The Maestro Project is a)*" good way to establish peer support. Fills a much needed support gap between child/adolescent and adult care."*

One participant recognized some deficiencies in the adult system, and had some suggestions for improving health care provision. *"I think the Maestro Project is an excellent beginning to getting people like me back on track with their diabetes. However, shortcomings elsewhere in the healthcare system are still a hindrance. I think at a bare minimum, offices need to start making reminder calls. Ideally, it would be nice to be able to correspond with a specialist via email or phone to discuss and implement treatment or renew prescriptions. That way people like I who have a tight budget don't need to miss work to receive the treatment they need."*

A pilot project for YA (16-25 years) with type 1 diabetes was initiated in Winnipeg in January 2006 at a local DEC, in an effort to improve service delivery and focus on client-centered care. The clinic is currently running one evening per week with a nurse, dietitian and counselor, with an endocrinologist on site once monthly. The program is targeted at YA who had previously fallen-out of medical care and graduates of the DER-CA who were identified in pediatric care as being at high-risk to drop out. The

program will be evaluated in early 2007 by a telephone survey and chart review. It is unknown at this time if this project will be sustainable or if it will be possible to broaden its availability to include all interested YA with type 1 diabetes in Manitoba, if it is proven to be successful in its current form.

4) Continuity of Services: "Coordinated and consistent care/intervention/action is provided across the continuum of services over time."

Reid (2002) describes three types of continuity: continuity of information, of personal relationships and of clinical management. Informational continuity refers to using information on prior events to provide care appropriate to the patient's current circumstances. Relational continuity recognizes the importance of an ongoing relationship between patients and health care providers and management continuity ensures that care received from different providers is connected in a coherent way.

Children's Hospital at the University of Parma, Italy provides an excellent example of continuity of care during transition, as was previously discussed (Vanelli 2004). The authors identified several fundamentals for a successful transition including gradual preparation of YA and their parents to change, keeping parents involved in the transition process, previous personal contact with the adult physician, movement to the adult clinic held in the same hospital, the presence of the pediatric specialist at the first visit to adult care and the seeing the same adult physician at all subsequent appointments. Strong collaboration between specialists was also felt to be a key to their success.

A transition program such as that described in Italy is not currently available in Manitoba. At the last visit to the DER-CA, the pediatric endocrinologist refers the YA to an adult endocrinologist and DEC via a summary/transfer letter. This letter is also copied to the family physician and any other specialty physicians that may be involved to inform

them of the transfer to adult diabetes care. However, there is no relational continuity; YA have no personal contact with any adult care providers prior to transfer and there is no longer any contact with the pediatric team after transfer. At their final pediatric visit the adolescent is given the names of their new adult endocrinologist and DEC and is generally told that they will be contacted with an appointment either by mail or telephone. There may be an transitional period between transfer from the DER-CA and the first appointment with the adult team of up to six months where the patient may not know who to call for help if needed or if they need prescription refills; they know they have graduated from pediatric care, but have not yet met anyone in the adult system and so do not feel comfortable calling them (or do not know who they should call).

The results of the present study showed that at the time of survey, less than 60% of participants were still receiving care from the same adult health care providers that they had originally been referred to at the time of transfer from the DER-CA. In Pacaud's 2005 study, 15% of her respondents had seen three or more adult doctors before establishing regular follow-up. In the audit of clinical records of the present study, large gaps of time existed in many participants' records as a result of switching endocrinologists. There was little evidence of informational or management continuity as no letters of transfer or summaries of previous care accompanied the participant from the previous physician to the new one. There was also little written communication evident in the medical record between the physician and the education team, if one was involved.

Many participants expressed difficulty with establishing relationships with their new health care team after transfer. *"I didn't like going for my check-ups. The doctor made me feel guilty about my diabetes, and the RD was too busy."* A 22 year old female

from the Direct group wanted to know why she had to keep going to appointments with doctors and educators; "*I'm healthy*" and "*I know what I'm doing.*"

The 2003 CPGs discuss interventions that have been shown to improve the efficiencies in the Diabetes Health Care (DHC) setting, including "the establishment of a centralized, computerized database system that improves transfer of information among all members of the DHC team, including the person with diabetes (page S14)." This is not currently available in Manitoba. However, as effective as a central database system may be, Pacaud (2005, page 183) stresses "simple measures, such as reminder telephone calls or follow-up calls after missed appointments could have a significant effect on continuity of care."

5) Effectiveness: "Services, interventions or actions are based on evidence from the current and evolving state of knowledge, and achieve the desired outcomes."

There was a widespread perception expressed by participants of the Maestro Project that it is a "*waste of time*" to follow-up regularly with an adult DEC. Young adults reiterated that it is hard to make time in a busy schedule for an extra appointment that they do not see as providing any benefit. Many YA reported feeling that they know more about type 1 diabetes than the educators. The majority of patients that an adult diabetes educator will see have type 2 diabetes with associated complications. As such, it is very difficult to gain experience and maintain a level of expertise with type 1 diabetes. For example, a 25 year old female from the Delayed group was very frustrated with her rural DEC. She reported to the MPC that the educators "*used me to confirm information as opposed to teaching me things*".

"*The staff at the adult clinic was not knowledgeable – I was "taught" about recognizing lows etc. at my last visit... 8 years after I was diagnosed."*

Even participants who were obviously struggling with their diabetes did not perceive a need for education. A 26 year old male from the Delayed group had not seen an educator for years. During a routine endocrinologist visit he was switched to an intensified basal-bolus regime using insulin analogs. He proceeded to have three severe hypoglycemic episodes that each involved a trip to hospital (one involved respiratory arrest and one involved loss of consciousness for over an hour). Despite this, he was not really interested in educators and felt that his endocrinologist would refer if needed. A 24 year old male from the Delayed group also refused to see educators despite three incidences of severe hypoglycemia after drinking alcohol. An ambulance was called each time. He did finally accept a referral to an adult DEC after the last incident. From the audit of diabetes records in the current study, it was also apparent that differences in referral patterns in adult endocrinology exist. Some endocrinologists seemed to work fairly closely with education teams, while others seldom referred to educators.

The 2003 CPGs state "Evidence has demonstrated the benefit of a more direct role enhancement of the diabetes nurse educator to provide adjustment of diabetes medication in a timely manner through a physician-supervised transfer of function (page S15)." Most adult DECs do not operate under this transfer of function. Several participants reported that it was not beneficial to attend a DEC because the educators were unable to help them make changes to their self management, for example to prescribe a new insulin or change the doses of an existing regime. Participants reported that the educator would generally say "you have to talk to your doctor about that."

"They didn't help enough to spend the time and money to travel to see them."

It is evident from this study that at the time of transfer from pediatric care, many participants of the Maestro Project have not yet reached a level of maturity and

psychosocial development that is required to independently and successfully navigate through the complex and philosophically different adult diabetes system.

LIMITATIONS OF THE STUDY

The MPC, who has a working relationship with all of the participants, collected data for the database. Some participants may have altered their responses in a direction that they presumed to be desirable. There may have been recall bias in data collection or measurement error in the degree of accuracy or completeness of the information. Participants of the Maestro Project were self-selected, leading to potential selection bias. There was a low response rate to the survey (15%). The results of the study may not be generalized to all YA with type 1 diabetes. The YA population is transient and difficult to contact, as evidenced by the literature, which did result in undesirably high rates of attrition throughout the study period. Complete follow-up information was not available for 48 participants in the Delayed group (28.6%) and 20 participants in the Direct group (23.8%).

Given the study design and short duration of the Maestro Project, it was not possible to find a cause-and-effect relationship between participation and rates of chronic complications. In order to provide evidence that the project reduces complications, a large longitudinal study with a comparable control group would be necessary.

This is not a randomized control trial with a comparable control group. As such, there may be important confounders or effect-modifiers that are not controlled in the comparison of the "Delayed" versus "Direct" referral groups. One alternative would be to use administrative data such as that found in the Manitoba Health Services Commission (MHSC) administrative database. Accessing this database is beyond the

scope of this study; it also does not differentiate between a diagnosis of type 1 and type 2 diabetes, making extraction of data extremely difficult.

Economic evaluation of the Maestro Project is beyond the scope of this study.

CONCLUSIONS

The Maestro Project has helped reconnect the Delayed group with medical care, and although it has failed to maintain the high level of surveillance experienced by the Direct group while in pediatric care, it has reduced this group's first year fall-out rate. Taking into account the confounding factor of age/stage of development, the Direct group is better connected to the adult health care system than was the Delayed group at the same age. However, there is no strong evidence to suggest that this will translate into improved medical outcomes for participants. The study was unable to determine if the incidence of hospital admissions and acute complications decreased or if glycemic control improved as a result of the project.

Participants of the Maestro Project are willing to participate in this initiative and appreciate the community building and the access to support, information and services that the project provides, including the opportunity for social contact with other YA with type 1 diabetes. Some participants also felt that the Maestro Project helped them take better care of their diabetes.

"*The Maestro Project provides help and support for diabetics. If we need help or are not sure where to find answers (ex. need to see a counselor, new doctor, dietitian, etc.) the Maestro Project informs us of the steps we need to take to get the answers or help.*"

"*The regular check-ups by the Maestro Project Coordinator and the emails and the newsletters reminded me to make appointments with the doctors and look into new information about diabetic products (ex. new testing monitors).*"

"It is the best thing that anyone could be a part of. My last two years would have been very difficult without the Maestro Project."

"I found it easy to put my diabetes on the back burner, just put those appointments off until a better time. Just receiving that newsletter reminds me that it is my responsibility now. It reminds me that other people with type 1 are managing just fine and going through the same things as me. As well as providing great information and stories. Also just knowing that The Maestro is an email away if I have questions is a real relief."

Currently, transition from pediatric to adult diabetes care is guided more by organizational constraints in the health care system than by the developmental needs of YA. As a result, there is a discord between the expectations of the adult diabetes system and the psychosocial developmental stage of the YA. The Maestro Project has proven to be an effective bridge between two philosophically divergent health care systems; the Maestro Project encourages YA to take their first steps in the adult diabetes system, and provides a much needed safety net if they fall.

RECOMMENDATIONS AND DIRECTIONS FOR FUTURE RESEARCH

1) Long term sustainability must be found for the Maestro Project. Longitudinal research to track medical outcomes of this population should continue. Economic evaluation is a necessary component of future program development.

2) The University of Parma, Italy provides a model for successful transition (Vanelli 2004). Systems for improving continuity of care and collaboration between pediatric and adult services should be developed. This may include the organization of joint transition clinics or the expansion of the current pilot project clinic for YA with type 1 diabetes, in conjunction with the Maestro Project.

3) This study does not address the needs of YA with type 1 who were diagnosed after 18 years of age. Their medical outcomes and barriers to accessing services in the adult medical system is an area for future research.

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APPENDIX 1:

Adult Diabetes Services in Winnipeg Regional Health Authority

Diabetes Education Teams:

Diabetes Education Centre (at Health Sciences Centre): GA 248
Ph# 204-787-7852

St. Boniface General Hospital Department of Endocrinology: C5-109
Ph#: 204-235-3305

Youville Centre: 33 Marion Street
Ph# 204-233-0262

Endocrinologists:

St. Boniface Hospital: Clinic Ph#: 204-233-8568
Dr. Sora Ludwig
Dr. Beth Salamon
Dr. Bruce Roe

Health Sciences Centre:
Dr. Vincent Woo - Clinic Ph#: 204-787-2870
Dr. Cindy Richardson - Clinic Ph#: 204-787-2871
Dr. Gregoire Nyomba - Clinic Ph#: 204-787-2870

In Private Practice at Winnipeg Clinic:
Dr. Beth Salamon - Clinic Ph#: 204-957-3202
Dr. Vincent Woo - Clinic Ph#: 204-957-3218
Dr. Cindy Richardson - Clinic Ph#: 204-957-3398

Internal Medicine:

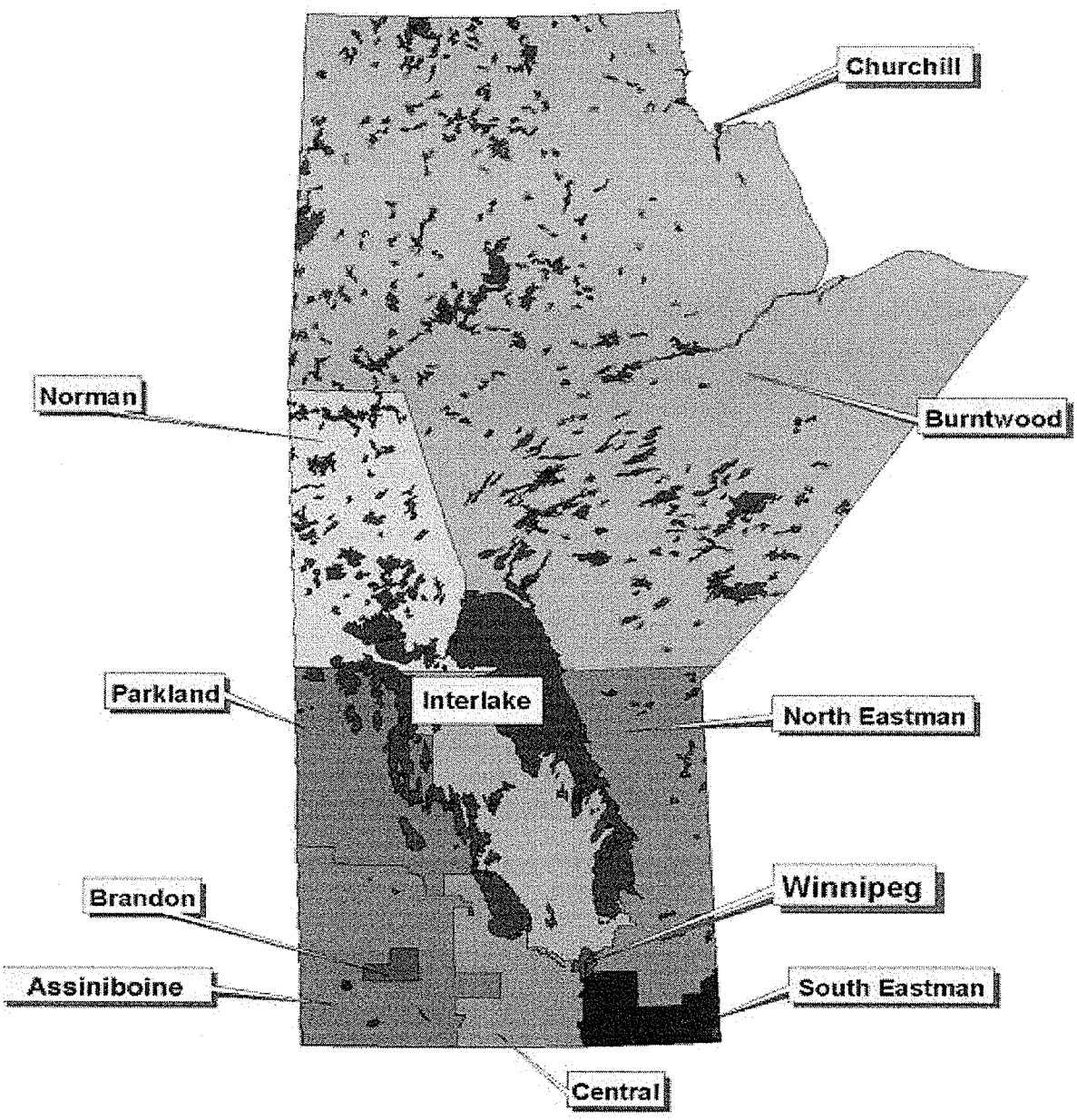
Dr. David Wiseman at Manitoba Clinic, 790 Sherbrook Street
Ph#: 204-788-5737
Dr. Harvey Lee at Medical Arts, Ph#: 204-338-0315 or 953-1270

Diabetes Research Group:

HSC University of Manitoba Campus, Ph# 204-789-3433

APPENDIX 2:

Diabetes Education Resources in Manitoba Regional Health Authorities



APPENDIX 2: (continued)

In Brandon RHA:
Prairie Health Matters
Unit A5 – 800 Rosser Ave
Brandon, MB R7A 6N5
Ph: 204-571-8357

In Assiniboine RHA:
Assiniboine RHA
Box 428
Rivers, MB R0K 1X0
Ph: 204-328-7101

Assiniboine RHA
Box 940
Killarney, MB R0K 1G0
Ph: 204-523-3234

In NOR-MAN RHA:
NOR-MAN RHA
Box 2550
The Pas, MB R0A 1M4
Ph: 204-627-8285

In Parkland RHA:
Parkland DER – North
Swan River Community
Health Service
Box 1028
Swan River, MB R0L 1Z0
Ph: 204-734-3769/6609

Parkland DER – South
Dauphin Community
Health Service
2nd Floor 317 Main St. North
Dauphin, MB R7N 1C5
Ph: 204-638-8622

In Churchill RHA:
Churchill RHA
Churchill, MB R0B 0E0
Ph: 204-675-8327

In North Eastman RHA:
North Eastman RHA
Box 550
Beausejour, MB R0E 0C0
Ph: 204-753-268-7464

In South Eastman RHA:
South Eastman RHA
Box 2560
Steinbach, MB R0A 2A0
Ph: 204-346-6143

In Interlake RHA:
Interlake RHA – North
Ashern Community Health Office
#43 Railway Ave (Box 310)
Ashern, MB R0C 0E0
Ph: 204-768-2585

Interlake RHA – South
446 Main Street
Selkirk, MB R1A 1V7
Ph: 204-785-4885

In Central RHA:
Central RHA
Box 610
Carman, MB R0G 0J0
Ph: 204-745-2021

Central RHA
Boundary Trails Health Centre
Box 2000
Winkler, MB R6W 1H8
Ph: 204-331-8841

Central RHA
25 Tupper Street North
Portage la Prairie, MB R1N 3K1
Ph: 204-239-3078

In Burntwood RHA:
Burntwood RHA
867 Thompson Drive S.
Thompson, MB R8N 1Z4
Ph: 204-677-5333

APPENDIX 3: Pediatric Diabetes Record Audit Form

Date of audit: _____

Gender: male female

Date of birth: _____

Date of diagnosis of type 1 diabetes: _____

Age at diagnosis of type 1 diabetes: _____

Date of transfer from DER-CA: _____

Age at transfer from DER-CA: _____

Date(s) of visits to DER-CA within the year before transfer to adult care:

	Date of visit	Date of visit	Date of visit	Date of visit
Physician				
Educator				

HbA1c results within the year before transfer to adult care:

Date	HbA1c

Diabetes related hospitalizations within the year before transfer to adult care:

_____

_____

_____

APPENDIX 4: Adult Diabetes Record Audit Form

Date of audit: _____ Location of audit: _____

Gender: male female

Date of birth: _____

Date of diagnosis of type 1 diabetes: _____

Age at diagnosis of type 1 diabetes: _____

Date of transfer from DER-CA: _____

Age at transfer from DER-CA: _____

Date(s) of visits to adult diabetes team within the year after transfer to adult care:

	Date of visit	Date of visit	Date of visit	Date of visit
Physician				
Educator				

HbA1c results within the year after transfer to adult care:

Date	HbA1c

Diabetes related hospitalizations within the year after transfer to adult care:

_____

_____

_____

APPENDIX 5: Survey of Participant Experience with The Maestro Project

Thank you for agreeing to complete this survey. Participants of the Maestro Project may use this survey to discuss their experience with the project and their transfer from the Diabetes Education Resource for Children and Adolescents (DER-CA). The results of this survey will be used by the Maestro Project to better meet the needs of participants. There are no right or wrong answers. Please feel free to add any additional comments.

A. Demographic Information:

Current age: _____ Sex: M F

Age at diagnosis of type 1 diabetes: _____

Education:
__ currently in high school
__ completed high school
__ did not complete high school
__ currently in university or college
__ completed university or college
__ other: _____

Employment:
__ working part-time
__ working full-time
__ not employed
__ part-time student
__ full-time student
__ other:_____

Current living situation:
__ parents __ partner/spouse
__ friend/roommate __ alone
__ other: _____

B. Personal Experience:

1) How old were you when you had your last appointment with the Diabetes Education Resource for Children and Adolescents (DER-CA)? _____

2) Were you referred to an adult diabetes doctor?
__ yes __ no (skip to question 5 if you answered "no")

3) Did you attend an appointment with this doctor within your first year after transfer from the DER-CA?
__ yes __ no
If no, why not?
_____
_____
_____

4) Are you still receiving medical care from this doctor?
__ yes __ no
If yes, how often? _____
If no, why not?
_____
_____

5) Were you referred to an adult diabetes education center (nurse, dietitian)?
__ yes __ no (skip to question 8 if you answered "no")

6) Did you attend an appointment with this education centre within the first year after transfer from the DER-CA?
__ yes __ no
If no, why not?
_____
_____

7) Are you still receiving care from this diabetes education center?
__ yes __ no
If yes, how often? _____
If no, why not?
_____
_____

8) Did you experience any difficulties or frustrations with establishing regular follow-up with your new health care providers after transfer from the DER-CA?
__ yes __ no
Please elaborate:
_____
_____
_____
_____

9) Has there ever been a time when you have gone for more than 1 year without any medical, nursing or dietitian follow-up for your diabetes?
__ yes __ no (skip to question 11 if you answered "no")
If yes, why?
_____
_____

10) What is the longest time period you have ever gone without having any medical, nursing or dietitian follow-up for your diabetes? _____
Was there a signifying factor that made you decide to reconnect with medical care? Please explain:
_____
_____
_____

C. Experience with the Maestro Project:

1) How did you hear about the Maestro Project?
__ Received a call or letter from the Maestro Project
__ Diabetes Education Resource for Children and Adolescents (DER-CA)
__ Adult Endocrinologist
__ Adult Diabetes Education Centre
__ Family Physician
__ Family/friend
__ Other: _____

2) Have you used any of the following services offered by the Maestro Project? (Please check all that apply):
__ Referral to endocrinologist
__ Referral to adult diabetes education team (nurse, dietitian or counselor)
__ Information on how to access an eye doctor
__ Information regarding prevention of other complications and/or required tests
__ Information regarding new research opportunities
__ Social contact with other young adults with type 1 diabetes – evening social events, coffee club, other organized activities
__ Newsletter __ Website
__ Other: Please describe
_____
_____

3) Before the start of the Maestro Project, where did you go for diabetes-related information and/or referrals?
_____
_____
_____

4) In your opinion, is there a need for the Maestro Project?
___ Yes ___ No
Why or why not?
_____
_____
_____
_____

5) Did you find that the Maestro Project was helpful in motivating or encouraging you to do better with your diabetes management?
___ Yes ___ No
Why or why not?
_____
_____
_____
_____

6) If the Maestro Project were discontinued, where would you go for diabetes-related information and/or referrals?

_____
_____
_____

7) Please describe in your own words what it is like to be a young adult with diabetes trying to become independent and self-reliant.

_____
_____
_____
_____
_____
_____
_____

8) Do you have any additional comments?

_____
_____
_____
_____
_____

Thank you for your time.

APPENDIX 6: Participant Informational Letter

Dear Participant:

As you know, ***Building Connections: The Maestro Project*** is a pilot project launched by the Winnipeg Regional Health Authority and the Health Sciences Centre Child Health Program to help young adults with type 1 diabetes as they move from pediatric to adult health care.

Norma Van Walleghem, RD, CDE, and Master of Community Health Science's student is doing the evaluation of The Maestro Project. Evaluation of this project is important because it will provide important feedback about your experience and will help decision-makers improve services for young adults in the near future.

The study will involve your completing a survey and the researcher reviewing your pediatric and adult diabetes charts. Enclosed you will find a survey and informed consent form from Norma. Your signature on this consent form is needed in order for the study to proceed. We would greatly appreciate your help in completing and returning the survey and consent form. Please feel free to call if you have any concerns or questions

Best Regards,

Catherine MacDonald,
Maestro Project Coordinator
(204) 789-3719

Norma Van Walleghem, RD, CDE
Master of Community Health Sciences Student
( )

Enclosure: Research Participation Information and Consent Form & Survey

APPENDIX 7:

Research Participant Information and Consent Form

Title of Study:	**Building Connections: The Maestro Project** **Evaluation of a Community Resource for Young Adults with Type 1 Diabetes**
Principal Investigator:	**Norma Van Walleghem, RD, CDE** Tel:
Co-Investigator:	**Dr. Michael Moffatt, MD, MSc, FRCPC** Executive Director, Research, Quality & Decision Support Winnipeg Regional Health Authority 1800-155 Carlton Street, Winnipeg MB Tel: (204) 926-7835

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to comprehensively evaluate the Maestro Project and explore the experience of participants in the project. The goals of the project are to increase the rate of medical follow-up and education for young adults with type 1 diabetes, reduce acute complications of diabetes and identify barriers to accessing medical care and education in the adult health care system.

A total of 200 participants will participate in this study.

Study Procedures

The study will involve your completing the enclosed survey and the researcher reviewing your pediatric and adult diabetes charts. Your signature on this consent form is needed in order for the study to proceed.

1) The survey includes questions about your experience with the Maestro Project and your transfer from the Diabetes Education Resource for Children and Adolescents (DER-CA). The study will involve your completing and returning a mailed survey to Catherine MacDonald, Maestro Project Coordinator. **It should only take 20 to 30 minutes of your time. Do not sign the survey.**

2) The study will also involve a review of your pediatric and adult diabetes medical charts for the year before and after your transfer to adult diabetes care. The following information will be obtained: HbA1c, dates of diabetes related hospitalizations and number of visits to diabetes educators and physicians.

A copy of the final report will be available to study participants upon request.

Risks and Discomforts

No mental, emotional or physical discomfort to the participants is anticipated with the study. The risks to participants are minimal.

There may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit young adults with type 1 diabetes in the future.

Costs

There are no costs to you to participate in this study.

Payment for Participation

You will receive no payment for taking part in this study.

Confidentiality

The Health Research Ethics Board of the University of Manitoba has approved this study. Only the researcher (Norma Van Walleghem) and her thesis advisor (Dr. Michael Moffatt) will have access to the completed anonymous surveys and information obtained from medical charts. Medical records that contain your identity will be treated as confidential in accordance with The Personal Health Information Act of Manitoba. The University of Manitoba Research Ethics Board and St. Boniface General Hospital may review records related to the study for quality assurance purposes.

Information gathered in this research study may be published or presented in public forums. However, at no time will it be possible to identify individuals in written or oral report, from this study. All study related documents will bear only your assigned study number.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre or your participation in the Maestro Project.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, contact the study staff:

Norma Van Walleghem at: ( )
Dr. Michael Moffatt at: (204) 926-7835

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Please check the statements that you agree with:

☐ I agree to have the researcher review my pediatric and adult diabetes medical charts.

I see my adult endocrinologist at (please check one):
- ☐ Health Sciences Centre
- ☐ St. Boniface Hospital
- ☐ Winnipeg Clinic
- ☐ Other:_____

☐ I agree to complete the enclosed survey

My signature below indicates that I am informed about the study and I am volunteering participate.

Date: _____

Name: _____ Signature: _____

Please return this consent form and the completed survey in the enclosed stamped, self-addressed envelope.

Thank you.