

Building connections for young adults with type 1 diabetes mellitus in Manitoba: Feasibility and acceptability of a transition initiative

Norma Van Wallegghem, Catherine A MacDonald and Heather J Dean

Abstract

During the transition from pediatric to adult diabetes care there is often a high rate of medical dropout and increased rates of acute and chronic complications. Building Connections: The Maestro Project was initiated in September 2002 by the Diabetes Education Resource for Children and Adolescents and the City of Winnipeg Regional Health Authority in Manitoba, Canada to examine the feasibility and acceptability of an administrative support and systems navigation service for young adults with type 1 diabetes. The participation rate on February 28, 2005 was 78.9% (373/473). Of the 323 young adult participants 18 to 30 years of age, 127 requested 230 community contacts for access care and education. Specifically, 46 re-referrals were made for specialty care (adult endocrinologists or general internists), 34 contact numbers were given for family physician care, and there were 121 contacts to reconnect with diabetes education and counseling services and 29 contacts for an optometrist. The first 2½ years of the project have demonstrated the feasibility and acceptability of this model of service for young adults with type 1 diabetes as they move from pediatric to adult care.

Key words: adolescents, transition, type 1 diabetes, young adults

Introduction

The transition from pediatric to adult health care is a period of increased vulnerability for young adults (YA) with chronic disease and one that presents unique challenges for them, their parents and the health care providers who serve them. While many YA with type 1 diabetes are successful in establishing support and ongoing follow-up after transfer, up to 50% of youth in this population have reported difficulties with transition.¹ Manitoba data confirms reports from other Canadian centers that 25% to 35% of YA are lost to medical follow-up within three years of transfer from pediatric clinics.²⁻⁷

The rate of acute complications, such as diabetic ketoacidosis (DKA) with excess morbidity and mortality, is high in this group and non-adherence to diabetes care can lead to severe chronic complications

before individuals reach the maturity of their late 20s.⁸ Despite intensive educational and management treatments, many are not successfully achieving optimal diabetes self care and face “worse than expected” long-term clinical and psychological outcomes.⁹⁻¹¹ Preconception counseling for young women with type 1 diabetes during this period is essential to achieving adequate glycemic control before and during pregnancy to prevent congenital anomalies.

In Canada from 1997–2000, there were 134 deaths in persons with diabetes age 20 to 29 years, a death rate more than three times higher than that of 20 to 29 year olds without diabetes.¹² A recent database study by Roberts¹³ confirmed this increased risk of death at a young age. YA 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. 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.¹⁴ It is important to note that, after diagnosis, DKA is 100 percent preventable. Deliberate insulin omission is the most common precipitating factor of DKA. Insulin omission may result from depression, which is two to three times more prevalent in people with diabetes, either due to abuse or neglect of the individual or in those going through teen rebellion. Omission may also result from “diabetes burnout”, needle phobia or fears of weight gain/eating disorder.¹⁵

Arranging effective transfer to adult medical services is now a necessary part of caring for all youth with chronic disease. This transfer may be difficult not only because of the chaotic and uncertain life stage, but also because of the fundamental differences in service delivery and in the philosophies of various allied health professionals, and the sometimes difficult integration between them. Studies have recently been published that used non-medical case management to encourage routine diabetes care visits, provide information and emotional support, monitor adherence and foster problem-solving skills in patients with type 1 diabetes without offering medical advice.^{16,17} Case managers were college graduates with no formal medical education, trained by the research and medical staff. In each study, the authors concluded that use of non-medical case management was a cost-effective approach to improving outcomes in their patients. This may

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prove to be an important model to provide seamless transition from pediatric to adult diabetes care, especially in places where no specialized clinic for YA with type 1 diabetes exists.

One of the goals of the 1998 Manitoba Diabetes Strategy was to develop a specialized, dedicated program for YA (age 18 to 25 years) with type 1 diabetes to assist in transition from pediatric to adult care.¹⁸ Until this goal could be attained, the Diabetes Education Resource for Children and Adolescents (DER-CA) and the City of Winnipeg Regional Health Authority's Young Adult Diabetes Working Group initiated and piloted a novel model of surveillance in September 2002 to facilitate transition for this vulnerable population. The program is called Building Connections: The Maestro Project. The objective of the program is to increase the rate of medical follow-up and education of YA with type 1 diabetes in the provinces of Manitoba, northwestern Ontario and southeastern Saskatchewan, and thus reduce their morbidity and mortality from complications of diabetes. The purpose of this article is to examine the feasibility and acceptability of this administratively based transitional support and systems navigation service for young adults 18 to 30 years of age with type 1 diabetes.

Diabetes care for children, adolescents and young adults in Manitoba

In Manitoba, 95% of youth with type 1 diabetes 0 to 18 years of age are followed at the DER-CA in a centralized program at Children's Hospital.^{19,20} The DER-CA team consists of three pediatric endocrinologists, one clinical associate, two clinical nurse specialists, two dietitians and a social worker, all certified diabetes educators. The team sees a youth three to four times annually and uses a case manager system to ensure coordinated care. A formal transition program is initiated for all youth at 13 years of age and continued until transfer to adult care at age 18 years. Transition topics include smoking, drugs, alcohol, driving, sexuality, contraception and pre-conception counseling and surveillance, as well as education on the potential long-

term complications of diabetes and options available for adult care. The DER-CA has a transition checklist and a resource booklet that is used in all stages of preparing for transition; these are given to the YA during their last visit to the center.

Presently, there is no centralized, coordinated, integrated program of care, nor education and support for individuals with type 1 diabetes in the adult care system in Manitoba. Approximately 80 youths are transferred annually to various adult medical clinics and education centers in Winnipeg and rural Manitoba. There are nine adult endocrinologists practicing in Winnipeg and a number of diabetes education teams across the province with varying levels of expertise in the care of YA with type 1 diabetes. Each regional health authority has a regional diabetes program, 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.²¹

Description of the transition program

The Maestro Project maintains a database of YA 16 to 30 years of age with type 1 diabetes in Manitoba, northwestern Ontario and southeastern Saskatchewan. The project provides a centralized, coordinated, community-based navigation service for the care, education and support of diabetes in Manitoba. The "Maestro", an administrative project coordinator, maintains telephone and e-mail contact with YA to provide the support and to help identify barriers to accessing appropriate health care services. The Maestro works closely with community-based resource centers in both Winnipeg and the regional health authorities involved in diabetes education to facilitate follow-up and referrals and enhance community linkages for service. Introductory letters were sent to all adult endocrinologists and diabetes education centers to promote the project and explain the referral process.

The Maestro Project initiated several alternate methods of service delivery for YA. These include a comprehensive Web site

(www.maestroproject.com), a bimonthly newsletter archived regularly on the project Web site, a casual evening drop-in group every four to six weeks and evening group educational dinner 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 on diabetes management, pregnancy, research, new technologies and other relevant topics in a relaxed, non-threatening, non-medical environment.

Method

Graduates of the DER-CA prior to the creation of the Maestro Project (i.e., from 1995 to August 31, 2002) with birth years between 1977 and 1984 were contacted by telephone and letter, inviting them to participate. Those graduating from the DER-CA after September 1, 2002 were referred with verbal consent to the Maestro Project at transfer to adult care. In August 2004, adolescents 16 to 18 years of age attending the DER-CA were given the option of early referral to the Maestro Project whereby they could receive the newsletters, take part in events and activities, and become familiar with the Maestro program. Referrals were also received directly from community physicians, diabetes educators and health workers. There were also self-referrals from YA diagnosed after age 18 years.

The Maestro contacted each participant biannually to inquire about the participant's access to care and diabetes services, as well as health status associated with any diabetes complications. During the first contact, the Maestro recorded baseline demographic information and recorded the following variables: date of last visit to physician; type of physician seen for diabetes care; number of visits to diabetes physician, other physicians, diabetes educators, psychologists, social workers or mental health workers, public health nurses or optometrists, and; date of last dilated eye exam or retinal photography. All information was self-report by participant and was related specifically to

the diabetes care and education received in the previous 12-month period prior to baseline assessment. If there had been no contact with any health professional in the previous 12-month period, the Maestro offered to reactivate and facilitate a referral to an adult endocrinologist and diabetes education center. During each subsequent follow-up contact, the Maestro repeated the same questions to record the number of medical and/or educational visits since the previous contact.

The Maestro also recorded the following self-reported medical 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, and 7) death. These self-reported medical outcomes will be used to describe the frequency of chronic complications in participants over time. These medical outcomes will be reported in future manuscripts, along with the outcome data on access to services in the community.

During every initial and follow-up contact, the Maestro also asked the following questions: "Is there anything else that I can help you with?" and "Do you have any questions for me?" The Maestro then recorded these anecdotes in the notes section of the database for diabetes-related concerns, problems and stories that were disclosed by participants. Anecdotes will be analyzed in 2006 by qualitative analysis for content and related themes and will be used to illustrate the perceived barriers to accessing medical care and education in the adult health care system for participants.

Results

Five hundred and twenty-six adolescents and YA were registered in the Maestro Project in the 30 months between September 1, 2002 and February 28, 2005. The Maestro excluded 53 YA who had died, moved out

of province, had had resolution of secondary diabetes or for whom contact information was unavailable (Figure 1). Thus, there was a total of 473 (i.e., 526 less 53) potential participants. Ninety-four YA were not responsive despite repeated efforts to contact by letter, telephone or e-mail (Group 2A & 2B). There were six other YA who declined participation (Group 2C). Thus, on February 28, 2005, the participation rate was 373/473 or 78.9%. Fifty of the 373 participants were age 16 to 18 years and were still followed at the DER-CA (Group 3A). The remainder of the activities of the project described in this report excludes this adolescent group. Forty-one of the remaining participants were aged 26 to 30 years (group 3C) and the descriptive activities of this group are included in the following results.

Of 323 participating YA age 18 to 30 years, 204 lived in the Winnipeg area and 108 lived in rural Manitoba. Eleven were from neighboring communities in northwestern Ontario and southeastern Saskatchewan, and were seasonally employed or were attending school in other provinces, but continued to receive their diabetes care and follow-up primarily in Winnipeg.

Of 323 participating YA age 18 to 30 years, 167 were graduates of the DER-CA before August 2002, 106 were referred directly to the project after September 2002 at graduation from the DER-CA, 30 were referred

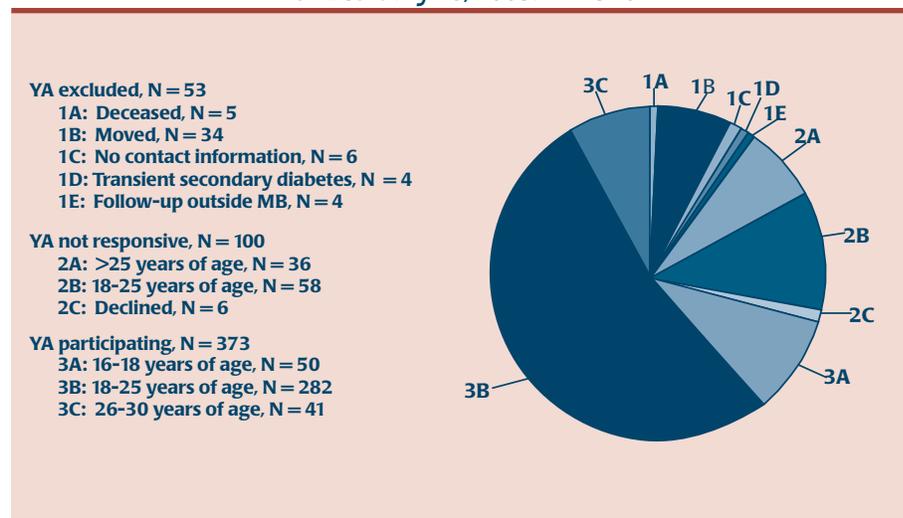
TABLE 1
Project referrals and community connections made within the Maestro Project from September 1, 2002 to February 28, 2005
Number of unique young adults = 127.

Number of referrals & community contacts	Total
To an endocrinologist	46
To a general practitioner	34
To a diabetes education centre	83
To a registered nurse	33
To a registered dietitian	1
To a social worker	4
To an optometrist	29
Total	230

by community health professionals and 20 were self-referred.

As seen in Table 1, of the 323 participants 18 to 30 years of age, 127 requested 230 community contacts for assistance to access care, education or optometry services. From September 1, 2002 thru February 28, 2005, 46 re-referrals were made for specialty care (adult endocrinologists or general internists) and 34 contact numbers were given for family physician care. Contact numbers were given out to 121 participants to reconnect with diabetes education and counseling services and 29 for optometrists. In addition to these direct community linkages, 111 partici-

FIGURE 1
Participation of young adults (YA) with type 1 diabetes in Maestro Project on February 28, 2005. N = 526



pants contacted the Maestro 203 times for other related information. Approximately 50 percent of the contacts occurred in the first nine months of the program.

Discussion

The passage from childhood to adult life is a very challenging time for young people and their families. 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.²² Efforts need to be made to ensure that YA and their families are well supported during this transition, thus building a strong foundation for their adult life. Strategies are also necessary to reduce the high rates of mortality and morbidity from preventable causes in this age group.

The concept of a “navigator” has been described in the literature.^{23,24} Different models exist, although common functions include assisting patients with accessing and coordinating services, providing emotional support and assisting with advocacy. The Maestro project is a unique program designed to lend this support and help YA and families navigate through the complex adult health care system. From the literature, it is clear that more research is needed to describe and evaluate the efficacy of different models of transition, such as this initiative. The first 2½ years of the Maestro Project have demonstrated the feasibility and acceptability of an administrative systems navigation service for YA with type 1 diabetes in Manitoba. The next phase is formal evaluation of the impact of this model on surveillance and medical outcomes.

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