

Evaluation of a Systems Navigator Model for Transition from Pediatric to Adult Care for Young Adults with Type 1 Diabetes

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Objectives: To determine if a systems navigator service, called the Maestro Project, could increase medical surveillance for young adults with type 1 diabetes who transfer from pediatric to adult care.

Methods: There were two cohorts of participants: 1) a younger group (age 18) who had the assistance of the navigator as they graduated from pediatric care (n=84) and 2) an older group (age 19-25 years) who were transferred to adult care without this initial support, but later enrolled in the program.

Results: 40% of the older group (who did not have initial access to the navigator) dropped out of adult medical care, compared to a drop-out rate of 11% of the younger group, who had access to the navigator at the time of transfer from pediatric care.

Conclusions: The systems navigator helped improve medical surveillance for both groups although there was no evidence of improved short term medical outcomes.

The passage from childhood to adult life can be challenging 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 needs and health care delivery systems. Current models have been ineffective in helping young adults with the transition from pediatric to adult diabetes care (1-8). *Building Connections: The Maestro Project* uses a systems navigator model to assist young adults with type 1 diabetes, age 18-25 years, as they transition from pediatric diabetes services in Manitoba, Canada. The systems navigator, an administrative project coordinator called The Maestro, maintains telephone and email contact with young adults to provide support and to help identify barriers to accessing health care services. The Maestro works closely with community-based diabetes education services in the province to facilitate follow-up and enhance community linkages.

The Maestro Project uses several methods of service delivery including a comprehensive website (www.maestroproject.com), a bimonthly newsletter, a monthly, casual evening drop-in group and educational events. These events are designed to encourage socialization with peers and to facilitate relationships with diabetes educators, endocrinologists, researchers, and other service providers.

The objective of the Maestro Project was to increase the rate of medical and educational follow-up for young adults with type 1 diabetes and thus reduce morbidity and mortality from complications. The initial phase of this project, the pilot study to test the feasibility and acceptability of this transitional support and systems navigator service has been published (9). The Maestro Project has been recognized as a promising practice model for this vulnerable population. The purpose of this brief paper is to report the

clinical outcomes and to identify barriers to care for young adults with type 1 diabetes after transfer from pediatric care in Manitoba.

METHODS:

A central database was created in August 2002 for two cohorts of participants in the Maestro Project: 1) a younger group (age 18) who had the assistance of the navigator as they graduated from pediatric care (n=84) and 2) an older group (age 19-25 years) who were transferred to adult care without this initial support. They were later enrolled in the program, 1-7 years after graduation from pediatric care.

The Maestro collected information from the participants by telephone every 6 months regarding medical or diabetes education visits, the presence of chronic complications, diabetes-related hospitalizations for diabetic ketoacidosis (DKA) or severe hypoglycemia, and barriers to accessing care in the adult diabetes system. Evaluation was completed Sept-Dec 2004 for the year before the Maestro Project was created and the year after the Maestro Project was in place. Sources of data included database review, audit of medical records, and a qualitative participant survey.

RESULTS:

The number of medical and diabetes educator visits was available for the year before and year after referral to the Maestro Project for 101/164 (62%) in the older group and 64/84 (76%) in the younger group.

As seen in Table 1, the systems navigator model helped the older group reconnect with adult medical services and helped the younger group reduce their first year fall-out rate after transfer from pediatric care. Prior to intervention from the navigator, over 40% of the older group had dropped out of adult medical care. This fall-out rate was lower in the younger group who had access to the

navigator at the time of transfer from pediatric care; only 11% of this younger group dropped out of adult medical care completely after transfer.

The younger group reported no long-term complications. The older group reported pregnancy loss of 38%; one case each of heart failure, legal blindness, and an amputation; 4 cases of proliferative diabetic retinopathy; 4 deaths (2 from DKA and 2 unrelated to diabetes). Both groups reported acute complications requiring visits to the Emergency Department or admission to hospital. For DKA, there were 3.0 cases/100 pt-yrs in the older group vs. 7.9 cases/100 pt-yrs in the younger group (NS). For severe hypoglycemia, there were 2.4 cases/100 pt-yrs in the older group vs. 4.7 cases/100 pt-yrs in the younger group (NS).

33% of the younger group and 42% of the older group experienced difficulties or frustrations with establishing regular follow-up with their adult health care team after transfer from pediatric care. Reasons for dropping out of care included difficulty scheduling appointments and knowing who to see, difficulty establishing relationships with the new team, feeling overwhelmed and lost in the system and a lack of perceived value.

100% of participants in the older group and 78% in the younger group felt that there was need for the Maestro Project. As of January 2008, there were 549 young adult participants. The Maestro Project had facilitated 374 referrals for 168 participants to endocrinologists, diabetes educators, mental health professionals and eye specialists and 198 individual participants had contacted the Maestro Project 515 times for information.

CONCLUSIONS:

At the time of transfer from pediatric care, many young adults are unable to independently navigate the adult diabetes system. The young adults who are enrolled in a systems navigator and support program

before age 18 years are better connected to the adult health care system than those who graduated before the program existed. In the first 2 years of the Maestro Project there was improved medical surveillance, but no evidence of improved short term medical outcomes. This may be due to specific characteristics of this young adult cohort, specific characteristics of service delivery in the adult care system, inadequate development or time for optimum evaluation of this model.

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Table 1: Medical and Educational Follow-up

# Visits Per Year	Older Group (n=101)		Younger Group (n=64)	
	Before Maestro	After Maestro	Before Transfer	After Transfer
Medical \geq 1	59.4%	73.3%	95.3%	89.1%
Educator \geq 1	25.7%	41.6%	92.2%	53.1%