

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

NORMA VAN WALLEGHEM, MSc, RD, CDE¹
 CATHERINE A. MACDONALD, BFA²
 HEATHER J. DEAN, MD, FRCPC³

OBJECTIVES— To determine whether a systems navigator service, The Maestro Project, could increase medical surveillance for young adults with type 1 diabetes who transfer from pediatric to adult care.

RESEARCH DESIGN AND METHODS— There were two cohorts of participants: 1) a younger group (aged 18 years, $n = 82$) who had the assistance of the navigator as they graduated from pediatric care and 2) an older group (aged 19–25 years) who were transferred to adult care without this initial support but later enrolled in the program.

RESULTS— Of the older group (who did not have initial access to the navigator), 40% dropped out of adult medical care, compared with a dropout rate of 11% for 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.

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The passage from childhood to adulthood can be challenging for young people and their families. For youth with type 1 diabetes, this transition is made more difficult because it is accompanied by changes in their health needs and health care delivery systems. Current models have been ineffective in helping young adults make 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, aged 18–25 years, as they transition from pediatric to adult diabetes services in Manitoba, Canada. The systems navigator, an administrative project coordinator called The Maestro, maintains telephone and e-mail contact with young adults to provide support and 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.maestro-project.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 ac-

ceptability 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 article is to report the clinical outcomes and to identify barriers to care for young adults with type 1 diabetes after transfer from pediatric to adult care in Manitoba.

RESEARCH DESIGN AND METHODS

A central database was created in August 2002 for two cohorts of participants in The Maestro Project: 1) a younger group (aged 18 years, $n = 84$) who had the assistance of the navigator as they graduated from pediatric care and 2) an older group (aged 19–25 years, $n = 64$) 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 care system. Evaluation was completed from September to December 2004 for the year before The Maestro Project was created and for 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 of 164 patients (62%) in the older group and 64 of 84 patients (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 to adult 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

From the ¹Diabetes Education Resource for Children and Adolescents, Winnipeg, Manitoba, Canada; ²Building Connections: The Maestro Project, Winnipeg Regional Health Authority, Winnipeg, Manitoba, Canada; and the ³Department of Pediatrics, Section of Endocrinology and Metabolism, University of Manitoba, Winnipeg, Manitoba, Canada.

Corresponding author: Norma Van Wallegghem, nvanwallegghem@exchange.hsc.mb.ca.

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Table 1—Medical and educational follow-up

| Number of visits per year | Older group (n = 101) | | Younger group (n = 64) | |
|---------------------------|--------------------------|---------------|---------------------------|----------------|
| | Before Maestro | After Maestro | Before transfer | After transfer |
| Medical ≥ 1 | 59.4 | 73.3 | 95.3 | 89.1 |
| Educator ≥ 1 | 25.7 | 41.6 | 92.2 | 53.1 |

Data are %.

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%; 1 case each of heart failure, legal blindness, and 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 room or admission to a hospital. For DKA, there were 3.0 cases per 100 patient-years in the older group versus 7.9 cases per 100 patient-years in the younger group (NS). For severe hypoglycemia, there were 2.4 cases per 100 patient-years in the older group versus 4.7 cases per 100 patient-years in the younger group (NS).

Of the participants, 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 rela-

tionships with the new team, feeling overwhelmed and lost in the system, and a lack of perceived value of adult care.

Of the participants, 100% of the older group and 78% of the younger group felt that there was a 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 to adult care, many young adults are unable to independently navigate the adult diabetes care 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, or inadequate development or time for optimum evaluation of this model.

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