

Problems in Transition From Pediatric Care to Adult Care for Individuals With Diabetes

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A B S T R A C T

OBJECTIVE

A previous survey in Montreal, Quebec, Canada, identified transition from pediatric to adult-care services for individuals with type 1 diabetes as problematic and, in certain cases, resulting in loss of medical follow-up. The present survey was conducted to establish the generalizability of the Montreal findings to Calgary, Alberta, a Canadian city in a different geographic region from Montreal and one using a different care-delivery model.

METHOD

Using the same questionnaire as was used in Montreal, patients with diabetes who had been transferred from the diabetes clinic at the Alberta Children's Hospital to adult-care services from June 1992 to June 1997 were surveyed (n=154). A modified Dillman method was used to conduct the survey.

RESULTS

The response rate was 61.8%. Usable data was available for 51% of the 154 eligible subjects. No significant differences relating to age of transition of diabetes care were noted between respondents from Calgary and those who participated in the previous Montreal survey. Similar problems in

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R É S U M É

OBJECTIF

Selon un sondage effectué antérieurement à Montréal (Québec), au Canada, la transition des services pédiatriques aux services de soins aux adultes chez les personnes atteintes de diabète de type 1 pose un problème et, dans certains cas, aboutit à l'arrêt du suivi. L'objet du présent sondage était d'établir si les données recueillies à Montréal s'appliquaient également à Calgary (Alberta), ville d'une région géographique canadienne différente et dont le modèle de prestation des soins est différent.

MÉTHODE

On a remis le même questionnaire que celui qui avait été utilisé à Montréal à des patients atteints de diabète qui étaient passés du centre de soins diabétologiques de l'hôpital *Alberta Children's Hospital* à des services de soins aux adultes entre juin 1992 et juin 1997 (n = 154). On a utilisé une version modifiée de la méthode Dillman pour effectuer le sondage.

RÉSULTATS

Le taux de réponse a été de 61,8 %. Les données chez 51 % des 154 sujets admissibles étaient utilisables. On n'a pas noté de différences significatives pour ce qui est de l'âge de la transition d'un type de soins à l'autre entre les répondants de Calgary et ceux de Montréal. Dans les deux villes, on a observé des problèmes de transition semblables, même si les modèles de prestation des soins sont différents.

CONCLUSION

Les résultats obtenus nous amènent à nous demander si les problèmes qui ont été observés pourraient être en partie attribuables à des questions de maturation psychosociale dont on n'a pas tenu compte au moment de la transition des soins.

transition of care were identified in both cities, despite different models of care delivery.

CONCLUSION

These results raise the question of whether identified problems may be due, in part, to psychosocial maturation issues that were not considered during transition of care.

INTRODUCTION

Patients with diabetes should take an active role in the management of their disease. The importance of good metabolic control for the immediate well-being of the patient and for reducing the risks of chronic complications is well established (1). Regular medical follow-up within a trusting and collaborative patient-doctor relationship is of prime importance for obtaining adequate metabolic control.

In a previous survey conducted in Montreal, Quebec, Canada, we identified difficulties in the transition from pediatric-care to adult-care services for patients with diabetes (2). In Montreal, pediatric diabetes care was provided through a diabetes clinic only. At the age of transfer, patients were referred to an adult diabetes clinic or endocrinologist. Of 135 Montreal patients surveyed, 33% experienced problems during transition, 28% experienced a loss of follow-up between their last pediatric-care visit and their first visit in adult-care services of >6 months and 13% experienced a loss of follow-up of >12 months. Overall, 50% of respondents either felt there was a problem or had a loss of follow-up for more than 6 months. It is unclear, however, if these findings would be generalizable to a different city in Canada with a different model for managing the transition from pediatric to adult diabetes care.

In Calgary, Alberta, Canada, at the time of this survey, pediatric diabetes care at Alberta Children's Hospital was shared between a diabetes clinic and the patient's family physician or pediatrician. At time of transition, diabetes care was transferred to an adult endocrinologist and ongoing care continued to be provided by the patient's family physician. Referral to an adult diabetes education centre was left to the discretion of the adult endocrinologist or family physician.

The present study investigated whether difficulties in transition from pediatric to adult care services among patients with type 1 diabetes in Calgary were comparable to those noted in the previous study in Montreal. It was hypothesized that similar difficulties would be present in the transition from pediatric-care to adult-care services independent of the setting, and that the transition problems reflected characteristics of this population of individuals with diabetes.

METHODS

The questionnaire and methodology used in the survey done in Montreal have been published elsewhere (2). To allow for direct

comparison, the present study used the same self-administered questionnaire as was used in the Montreal survey (Figure 1), with 3 minor changes: 1) the definition of regular follow-up and the loss of follow-up were modified to be consistent with local medical follow-up practices (see definitions below); 2) 1 question was deleted from the Calgary survey regarding whether the participant would be interested in being contacted again for future research on the same subject; and 3) ethics approval for the study was obtained from the Conjoint Health Research Ethics Board, University of Calgary, Calgary, Alberta, Canada.

During the winter of 1998, the questionnaire was mailed to the last known address of all patients with diabetes who had been transferred from pediatric-care to adult-care services by the diabetes clinic of the Alberta Children's Hospital from June 1992 to June 1997 (N=154). To optimize the response rate, the Total Study Design as described by Dillman (3) was used. A specific design for the cover letter and individual stamps (rather than bulk mailing) were used. A postcard reminder was sent 1 week after the first mailing of the questionnaire. If no answer was received from the participant after 4 weeks, a second mailing of the questionnaire was done.

The following definitions were used by both the Calgary and Montreal surveys to assess transition of care:

- *Transition between pediatric and adult care*: period between the last visit in pediatric care services and the establishment of regular medical follow-up in adult-care services.
- *Loss of follow-up*: delay of >12 months between 2 medical visits
- *Regular medical follow-up for diabetes*: ≥ 2 visits/year

Data were analyzed using SPSS for Windows software, (SPSS Inc., Chicago, Illinois, United States). Chi-square analysis for categorical variables and t tests for continuous variables were used to compare groups. Significance levels were set at $p < 0.05$. Results are presented as absolute numbers, percentages or means \pm standard error of the mean (SEM).

RESULTS

A total of 154 patients were transferred to adult-care services from the diabetes clinic at the Alberta Children's Hospital. Of these, 104 surveys were returned: 81 were completed, 2 of which were excluded from the analyses as they were completed by the parents. Twenty-three surveys were returned unopened as the current addresses of the patients were not known. Overall, the response rate was 61.8%

(81/131). Thus, usable data was available for 51.3% of the 154 eligible subjects.

The mean age of respondents at the time of completion of the questionnaire was 20.5 ± 2.2 years ($n=79$). The mean age of diagnosis was 8.9 ± 3.9 years ($n=79$). Seventy-five percent (60/79) of respondents had been referred to adult-care services, whereas 24% (19/79) had left the pediatric clinic without being referred elsewhere. These 2 groups did not differ in their responses to other questions in the survey (age at diagnosis, ideal age for transition, presence of a problem during transition of care, type of current follow-up and rates of loss of follow-up). The mean ideal age for transition suggested by respondents was 17.6 ± 1.6 years (range: 15 to 24). Of the respondents who were referred to adult-care services for follow-up of their diabetes, the mean age of referral was 17.2 ± 1.1 years (range: 14 to 19). When the participant's actual age of transition was compared with their suggested ideal age for transition, 20% indicated that they would have liked to have been transferred earlier; 42% felt that they had been transferred at the right age; and 38% would have liked to have been transferred later. These findings were similar to those reported in the Montreal survey (Table 1).

Forty-six percent of respondents expressed having experienced some problems with the transition from pediatric to adult care. Although 89% of respondents reported <12 months between their last visit to the pediatric clinic and their first

visit to the adult clinic, 31% reported a lapse of >6 months between those 2 visits. Eleven percent of the respondents were lost to follow-up (a delay of >12 months during their transition between pediatric to adult care). Fifty-two percent of respondents had either experienced a problem, had a delay of >12 months between their transition of care or had no current follow-up. When these results were compared with the Montreal survey results (Table 2), no significant differences were found between the 2 cities ($p>0.05$).

As shown in Figure 2, 28% were followed-up within a diabetes clinic, 32% by a family physician, 15% by an endocrinologist, and 11% by both an endocrinologist and a family physician. Fifteen percent of respondents had seen ≥ 3 doctors in adult-care services before they had established regular follow-up of their diabetes. Fourteen percent were without current follow-up. Although the percentage of subjects without follow-up was similar between the 2 cities, the distribution of types of follow-up differed, with a greater proportion of Montreal patients being seen by an endocrinologist.

Comments provided by respondents offered some insight into how they felt about the transition from pediatric to adult care. Some respondents did not feel that they had any problems with the transition, as they felt they had the ability to take control of managing their diabetes. For others, transition was affected by factors not directly related to the actual transition itself, e.g. moving to a different city. However,

Figure 1. Self-administered questionnaire used in the survey completed in Montreal

Birth date (YY/MM/DD): _____

At what age were you diagnosed with diabetes? _____

Were you referred to an adult-care service for the follow-up of your diabetes? () Yes () No

If yes, at what age were you referred to adult-care services? _____

In your opinion, what would be the ideal age for this transition? _____

Did you experience any problems with this transition? () Yes () No
(If you wish to elaborate, please use the back of this sheet.)

How long was the time lapse between your last visit to the pediatric clinic and your first visit to the adult clinic for your diabetes? _____

Date of your last visit to the pediatric clinic: _____

Date of your first visit to the adult clinic: _____

How many different doctors did you see in adult-care services before establishing a regular follow-up of your diabetes (2 or more visits per year)? _____

Are you now followed: () in a diabetes clinic (specialized clinic)
() by an endocrinologist or internist
() by a family physician
() no regular follow-up

If no regular follow-up, do you wish to obtain a new referral to the diabetes clinic of your choice? () Yes () No

Please return the completed questionnaire in the self-addressed stamped envelope as soon as possible.
Thank you for your collaboration.

there were numerous negative comments regarding transition. Many respondents felt that the transition was rather abrupt, that they had gone from a tightly controlled, easily accessible pediatric-care service to a situation where they had to make decisions about their care with much less guidance. Other problems that were noted with transition included lack of information and resources, lack of coordination between the different physicians and specialists the patients were required to see (dietitian, endocrinologist, family physician), difficulty accessing physicians to ask questions, and the lengthy waiting period from the time of the appointment to seeing the physician.

DISCUSSION

The findings of this Calgary-based survey on transition from pediatric-care to adult-care services for individuals with diabetes were very similar to the results of the previous study conducted in Montreal, despite the 2 centres having different care-delivery models. Similar frequencies of problems with respect to transition of care were seen in both Calgary and Montreal. These findings suggest that the reasons for these problems may be related to the patient population rather than to the healthcare delivery model being used. This is an important distinction, as it suggests that programs that attempt to improve the transition from pediatric to adult care of young adults with type 1 diabetes should consider and address the specific characteristics of this population that may underlie transition difficulties.

Reported rates of loss to follow-up in previous studies have been between 24 to 69% (4-6). The lower rates of loss to follow-up seen in our study may be due to the ascertainment method (self-reported questionnaire vs. chart review, and definition used) and participation bias. Nevertheless, even though our reported rates are somewhat lower, the high rate of problems in transition identified by our respondents

is suggestive of deficiencies in the transition process in both Calgary and Montreal. This high rate of problems in transition of care becomes more significant as loss to follow-up is known to be associated with poorer metabolic control and increased risk of hospitalization related to acute diabetes complications (4,5).

Expert organizations involved in adolescent care have recently issued position statements regarding the need for planned and organized transition to adult care for adolescents and young adults with chronic diseases (7,8) and in particular, diabetes (9,10). The International Society for Pediatric and Adolescent Diabetes Consensus Guidelines (10) provide more detailed guidance with the following 3 specific recommendations: 1) negotiation and liaison between 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; and 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. However, data on the best model for transition of care are lacking.

At the time of the surveys, neither Calgary nor Montreal had a specific transition clinic or program. Although different models for transition of care have been proposed (6,11-13), few studies have examined the impact on patients' overall care. Orr and colleagues (14) reported no deterioration of metabolic control in patients transferred to a young adult program that empowered patients to manage their diabetes independently before moving on to regular adult care services. However, their analysis did not include comments on the rate of loss to follow-up in the transition clinic. Kipps and colleagues (15) compared 4 models of transition of care within the Oxford region, United Kingdom: 1) transfer to an adult clinic; 2) transfer to a young adult clinic held at a

Issue	Calgary (n=79)	Montreal (n=135)
Mean age at transition (years)	17.2±1.1	18.5±1.1
Mean ideal age for transition (years)	17.6±1.6	18.8±1.7
Would have liked to be transferred earlier (%)	20	21
Were transferred at the right age (%)	42	39
Would have liked to be transferred later (%)	38	40

*No statistical difference was found between the 2 cities

Problems	Calgary (n=79)	Montreal (n=135)
Problems during transition reported by patients (%)	46	33
Interruption of care** (%)	11	10
Currently without regular follow-up (%)	14	13
Either expressed having a problem or had a loss of follow-up (%)	52	50

*No statistical difference was found between the 2 cities.

Results expressed as a percentage of respondents

**Defined as a delay of >12 months between 2 medical visits

different hospital; 3) transfer to a young adult clinic held in the same hospital; and 4) transfer first to an adolescent clinic (run by the pediatrician and the adult physician) before transfer to an adult clinic in the same hospital. There were no differences in metabolic control after transition between the 4 models. However, the individuals from all 4 models who were lost to follow-up had higher glycosylated hemoglobin (A1C) values during the 2 years prior to transition of care. This suggests that this poorly controlled population may be particularly vulnerable to loss to follow-up. Follow-up of these patients 2 years after transition of care indicated that a greater proportion of patients in the first 2 models of transition (43 and 71%, respectively) were not followed regularly within specialized diabetes clinics compared with the 2 last models (29% and 37%, respectively). Furthermore, a greater proportion of subjects were not satisfied with the transfer of care in the first model (47%) compared with the 3 other models (12%, 4% and 12%, respectively).

A limitation of the initial survey in Montreal was the low response rate (44%). For the current survey, a better overall response rate (62%) was achieved. A response rate <60% raises concerns about the characteristics of those who participated compared with those who did not (3). Due to the confidential nature of the survey, it was not possible to determine if the survey respondents were representative of the whole population. It is conceivable that nonrespondents may not have had problems in transition and, thus, did not feel a need to express themselves. Alternatively, they may also have had similar difficulties. The fact that the results were so similar in both Calgary and Montreal provides support for the validity of the findings.

Other studies have explored specifically the attitudes of young adults towards transition clinics. Court (16) commented on the need for a transition clinic to meet the special needs of young adults. In his survey, identified needs were confidentiality, privacy, informality, information, short waiting periods and a telephone consultation service. Eiser (17) reported a good degree of satisfaction in a clinic for those

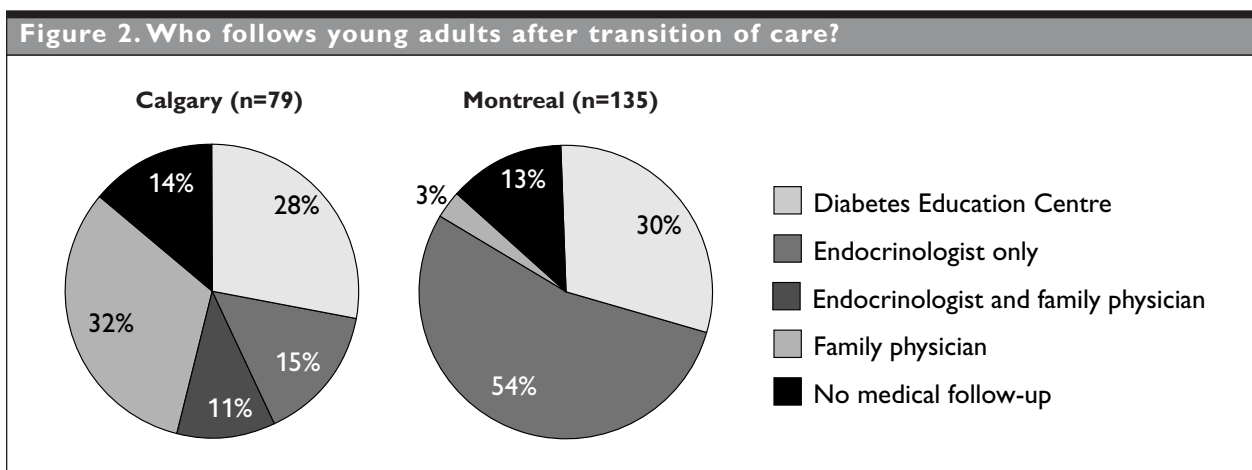
<25 years of age that was set up in the same hospital as the pediatric clinic. However, respondents were recruited from the list of patients attending this clinic for young adults. Thus, patients who never reached the clinic or who were lost to follow-up were never contacted, resulting in a selection bias. On the other hand, Wilson and colleagues (6) found that after an initial success, the attendance at their young adult clinic fell to levels similar to those seen in young adults attending regular adult clinics. New labour-intensive strategies were required to reach and bring back non-attenders to medical care. This last study illustrates the need for proactive, enthusiastic and energetic intervention on the part of healthcare providers in order to maintain medical follow-up for young adults with diabetes.

CONCLUSION

Surveys from 2 different regions of Canada, with different diabetes care delivery models, confirmed the presence of similar difficulties in transition from pediatric to adult care. Our data lead us to question whether these problems may be due, at least in part, to psychosocial maturation issues that were not considered during the transition of care. Whether current transition models and recommendations address these issues is not known. Based on our findings, we concur with the following Society for Adolescent Medicine recommendation: "Further research is required to address a number of unanswered questions. Research that would examine health outcomes, functional and long-term outcomes and cost-benefit issues is especially needed." (8)

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