Exploring a black hole: Transition from paediatric to adult care services for youth with diabetes

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During the passage from adolescence to adulthood, individuals are expected to go through three psychological stages: identity formation (finding out who they are), intimacy (establishment of stable intimate relationships) and generativity (productive lifestyle, career or vocational realization). Having diabetes may complicate this process. Further, the period of late adolescence and early adulthood coincides with the transition of care from paediatric to adult care services. This transition is a time when the individual is particularly at risk for loss of medical follow-up and medical complications. The present article reviews the current state of knowledge on psychosocial maturation in youth with diabetes and the process of transition of care from paediatric to adult care services.

Key Words: *Adolescence; Transition of care; Type 1 diabetes; Young adults*

L'exploration d'un trou noir : La transition des soins pédiatriques aux soins pour adultes pour les jeunes diabétiques

Au passage de l'adolescence à l'âge adulte, les individus devraient traverser trois phases psychologiques : la formation de l'identité (découverte de qui ils sont), de l'intimité (établissement de relations intimes stables) et du souci de pérennité (vie productive, réalisation de carrière ou de formation professionnelle). Le diabète peut compliquer ce processus. De plus, la période de la fin de l'adolescence et du début de l'âge adulte coïncide avec la transition des services de santé pédiatriques aux services pour adultes. Cette transition représente un moment auquel l'individu risque énormément d'être perdu au suivi et de souffrir de complications médicales. Le présent article permet d'analyser l'état actuel des connaissances sur la maturation psychosociale chez les jeunes diabétiques et le processus de transition des soins des services pédiatriques aux services pour adultes.

During the passage from adolescence to adulthood, individuals are expected to go through three psychological stages as described in Erickson's theory (1): identity formation (finding out who they are), intimacy (establishment of stable intimate relationships) and generativity (productive life style, career or vocational realization). More recent developmental psychological theory (2,3) subdivides this period into two further phases: an early phase, corresponding to the years after high school and associated with transitioning away from the parental home geographically, economically and/or emotionally; and a later phase, associated with a maturing sense of identity and more mature adult roles in society (intimacy, employment, parenting, etc). Having diabetes may complicate the process of achieving identity, intimacy and generativity. Unfortunately, neither paediatricians nor adult physicians are well prepared to face the special developmental challenges of young adults with chronic diseases, and literature on the special medical needs of this phase of life is just starting to emerge.

A longitudinal study by Jacobson et al (4) suggested that adolescents with diabetes have a delay in ego development. In their discussion of these findings, the authors mentioned the negative effect that the threat of future complications might have on diabetic adolescents' ego development and their capacity to imagine their future life. Two other reports (5,6) suggested a further delay in social maturation among young adults with diabetes at both the intimacy and the generativity stages. Subjects with diabetes were less likely to be dating or married than were control subjects. The subjects with diabetes were more likely to have always lived in their parental home or to have returned to live with their parents and to still be financially dependent on their parents. Finally, parents of these subjects were more involved in their health care. In contrast, two studies (7,8) including subjects with various chronic diseases, not exclusively diabetes, found that most adolescents with common chronic diseases had successful transitions to adulthood, with levels of psychosocial well-being, education, and marriage or dating similar to those of their peers without chronic diseases.

Researchers examining the educational achievement and employment status of young adults with diabetes have reported conflicting results. Although some studies found no differences (9-11), other studies found higher rates of unemployment (12,13) and lower educational achievement

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(10) in young men with diabetes. These findings only suggest a possible delay in maturation and not permanent deficiencies because Pless et al (8) found no difference at 36 years of age.

Diabetes management includes following a meal plan, daily blood glucose monitoring and multiple daily insulin injections, which can all be difficult to maintain through the developmental stages of early adulthood. Young adults show decreased adherence to their treatment compared with younger and older age groups (14). The level of adherence measured by the Self-Care Adherence Inventory has been found to be directly linked to metabolic control in different age groups (15-17). Improved adherence has also been observed with increased diabetes-specific social (18) and family (19,20) support. Positive family support has been shown to influence metabolic control of diabetes, in both paediatric and adult populations (19,21,22). The timing of the transfer of responsibility for diabetes tasks and treatment from the parents to the adolescent is also crucial and varies from one individual to another. Wysocki et al (20) have shown that adolescents who are left responsible for their treatment too early have poorer metabolic control. The best metabolic control was seen in the families with comprehensive sharing and gradual transfer of responsibility to the adolescent. Thus, psychosocial maturation in adolescents with diabetes may be influenced by how and when they assume responsibility for their treatment.

For patients with diabetes, regular medical follow-up within a trusting and collaborative patient-doctor or team relationship is of prime importance in obtaining adequate metabolic control, which ensures well-being and a reduction of the risks of chronic complications (23). Several reports have identified late adolescence and early adulthood as periods with higher rates of acute complications and relative mortality risks for individuals with diabetes (24,25). The period of late adolescence and early adulthood coincides with the transition of care from paediatric to adult care services. This transition is a time when the individual is particularly at risk for loss from medical follow-up (reported rates in young adults of 11% to 69%) (26-29). This loss of medical follow-up is known to be associated with poorer metabolic control and increased risk of hospitalization related to acute diabetes complications (26,27).

Several expert organizations involved in adolescent care have issued position statements regarding the need for a planned and organized transition to adult care for adolescents and young adults with chronic diseases (30,31), and for diabetes mellitus in particular (32,33). The International Society for Pediatric and Adolescent Diabetes' 2000 consensus guidelines (33) provide more detailed guidance with the following three specific recommendations: there should be negotiation and liaison between the paediatric and adult services, including, when possible, the organization of joint clinics; a decision should be made 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 the adolescent should be prepared for the 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. Nevertheless, there is still a paucity of data on the best model for the transition of care.

Although different models for transition of care have been proposed (28,34-36), only a few studies have examined the impact on the patients' overall care. Orr et al (37) report no deterioration of metabolic control in patients transferred to a young adult program empowering 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 et al (38) compared four models of transition of care within the Oxford region of the United Kingdom: transfer to an adult clinic, transfer to a young adult clinic held at a different hospital, transfer to a young adult clinic held in the same hospital, and transfer first to an adolescent clinic (run by the paediatrician and the adult physician) before transfer to an adult clinic in the same hospital. There were no differences in metabolic control after transition among the four models. However, the individuals from all four models who were lost to follow-up had higher levels of hemoglobin $A1_c$ during the two years before the transition of care. This suggests that this poorly controlled population may be one that is particularly vulnerable to loss to follow-up. Follow-up of these patients two years after the transition of care indicated that a greater proportion of patients in the first two models of transition (43% and 71%, respectively) were not followed regularly within diabetes-specialized clinics compared with the last two models (29% and 37%, respectively). Further, a greater proportion of subjects were not satisfied with the transfer of care in the first model (47%) compared with the three other models (12%, 4% and 12%, respectively).

A few other studies looked specifically at the attitudes of young adults toward transition clinics. Court (39) commented on the need for the transition clinic to meet the special needs of young adults. In his survey, these needs were identified as confidentiality, privacy, informality, information, short waiting periods and a telephone consultation service. Eiser et al (40) reported a good degree of satisfaction in a clinic for individuals younger than 25 years of age set up in the same hospital as the paediatric clinic. 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 Greenhalgh (28) found that after initial success, the attendance to their young adult clinic fell to levels similar to those of young adults attending regular adult clinics. New labour-intensive strategies were required to reach and bring back nonattenders to medical care. The paper by Wilson and Greenhalgh (28) illustrates the need for proactive, enthusiastic and energetic intervention on the part of the care providers to maintain medical follow-up for young adults with diabetes.

The best results appear to be obtained within formal transition clinics; however, these are often difficult to organize and sustain. Diabetes care providers need to find alternative strategies to ease the transition within existing structures. On the paediatric side, the process of transition of care needs to be started early by systematically discussing expected developmental stages and age-specific challenges with all patients and families. Progressively changing from visits with the adolescent and his parents to visits mostly done with the adolescent or young adult on their own will help with the transition of responsibility for diabetes care within the family. As the time to referral to adult care services approaches, the paediatric team needs to describe the adult services available to the adolescent or young adult, and explain the differences between these services and the paediatric services the patient is used to. This should be done in a positive way. Differences in the environment (such as waiting rooms with sick patients with complications rather than with younger children) should also be discussed. Depending on the setting, it may be helpful to have the paediatric team organize the first appointment for the family. It ensures timely follow-up and is less intimidating for the patient. Once the adult service team members see the patient, a resource person from the paediatric team should be available for follow-up with patients and to offer help to those who have fallen out of care or need help to reorganize their follow-up (eg, new referral).

The adult diabetes care team needs to recognize the special features of young adulthood. This is a phase of life that is often disorganized, with a hectic and unpredictable schedule. Further, the young adult often feels invincible and may not recognize the importance of ongoing intensified diabetes management. On the other hand, they may directly reject intensified diabetes management for different reasons, such as rejection of parental control, diabetes burnout, or fear of hypoglycemia or weight gain. In these years of newly achieved independence, controlling figures and attitudes will likely be rejected. Adult endocrinologists are expected to change the therapy when performing consultations for family physicians. In the case of transfer from paediatricians, major changes at the first consultation, rather than being seen as a positive sign of the usefulness of the consultation, may be perceived as a lack of respect for the paediatrician's level of competence. A more gradual shift toward the local approaches to diabetes care may be warranted. Therefore, the diabetes care team needs to present itself as a guide to help with problem-solving and individualization of self-care rather than as the traditional patriarchal and directive figure it often adopts in medical care.

CONCLUSIONS

The transition from paediatric to adult care frequently results in a loss of follow-up from medical care, as well as anxiety and frustration for the young adult with diabetes and his or her family. In each centre, a specific plan of action should be prepared to ensure that the paediatric team adequately prepares the adolescent for transfer, and that the adult service team recognizes and addresses the special needs of this population.

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