

In Brief

The transition to adult-centered care occurs at a crucial and vulnerable time for adolescents with type 1 diabetes. Despite the importance of transition care, scant literature exists examining different models of transition care and their impact on health outcomes in adolescents with type 1 diabetes. Loss to follow-up, increased hospitalizations, and deterioration in metabolic control are likely mitigated by structured transition programs.

Moving On: Transition of Teens With Type 1 Diabetes to Adult Care

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Whereas “transfer of care,” in essence, refers to the act of handing over care from one physician or health care team to another, “transition of care” is far more involved with the before-and-after events surrounding transfer. The transition to adult medical care has long been defined by the Society of Adolescent Medicine as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-centered health care systems.”¹ The ultimate goal of such a transition is seamless, comprehensive, and developmentally appropriate health care throughout. Yet all too often, the partnership between those saying goodbye to emerging adults and those welcoming them is tenuous at best. E.A. Coleman put it succinctly as follows: “Complex problems like improving care transitions rarely can be solved with simple solutions.”² In this article, we address the transition of adolescents with type 1 diabetes from child- and family-centered care to adult-centered care.

The 2008 clinical practice guidelines of the Canadian Diabetes Association³ recommend that, “To ensure ongoing and adequate metabolic control, pediatric and adult diabetes services should collaborate to prepare adolescents and young adults for the transition to adult diabetes care.” This recommendation is supported by Grade C evidence, Level 3,⁴ but it fails to provide advice on the more practical hows and whens of transition.

We focus here on three aspects of transition: 1) a model of life transitions first proposed by Hopson and Adams⁵ that highlights the complex psychological and psychosocial upheavals inherent in such transitions, 2) a brief review of the diabetes literature on the outcomes of transition, and 3) a review of the impact of interventions on these outcomes.

Transition: It’s More Than Just Crossing the Road

More than 30 years ago, Hopson and Adams⁵ proposed a model of transition in an attempt to understand and manage personal change. An adaptation of this model is depicted in Figure 1. It fits well with many of the experiences witnessed with the transition of adolescents with diabetes and their families from pediatric to adult health centers.

Adolescents are often excited to move on in their lives, leaving the crowded waiting room of the children’s hospital behind (represented by the solid line labeled “a” in Figure 1). Their parents, on the other hand, often are much more loathe to cut the apron strings (represented by broken line “b” in Figure 1). The timeline for what is termed “re-construction and recovery” is, in reality, much more variable than that depicted in Figure 1 and will depend, at least to some extent, on what else is happening in the lives of these adolescents and their families. The move from high school, whether to university, college, another training facility, or into the job market, plus

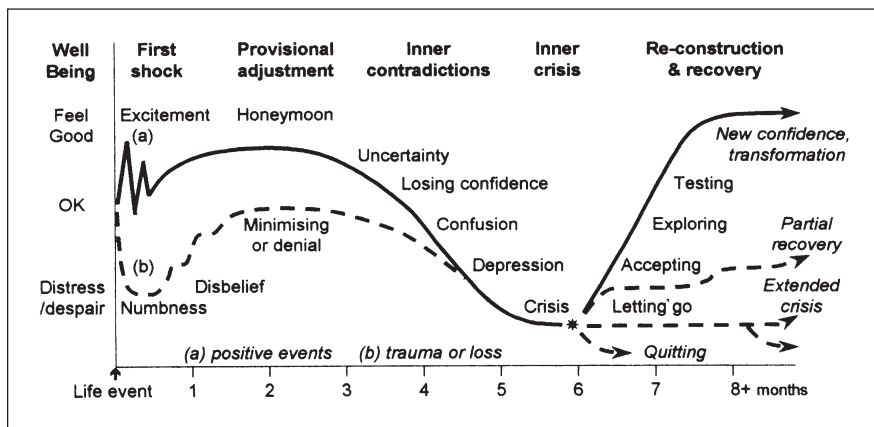


Figure 1. Model of impact of personal change as developed by Hopson and Adams in 1976.⁵

the presence of other stressors, makes transition a much greater challenge.

Why, then, if it is potentially so traumatic and personally so disruptive, is transition necessary, and when should it occur? The majority of children and young teens in developed countries receive their diabetes care in the context of pediatrician-driven interdisciplinary health care teams (pediatric endocrinologists in North America and pediatric diabetologists in many other countries). Maintaining indefinite care of these youth is not necessarily in their best interests given the differences between child- and family-centered approaches and adult-centered approaches to care. In addition, the vast majority of pediatricians are not trained in the treatment of complications, but rather in surveillance for early changes. In many places, it is also a capacity issue, and policies about the timing of transition are very prescriptive (e.g., in the Province of Ontario, Canada, individuals > 18 years of age are not admitted

to a children's hospital except under exceptional circumstances).

This highlights an important issue: timing of transition should be situation-dependent. In many countries, especially those in which adolescent medicine is not recognized as a pediatric subspecialty, transition often occurs around the time of puberty (12–16 years of age). In others, it occurs at 16–18 years of age, and in some countries, no rules define the timing of transition.

In our opinion, transition to adult care requires a more common-sense approach that combines two important principles: 1) timing of transition should occur at a maturational stage of demonstrated effective self-care rather than at an arbitrary chronological age and 2) multiple simultaneous transitions (i.e., health care transition plus completion of high school and moving away from home) are likely to significantly enhance the risk of patients dropping out of ongoing care. Should adolescents leave their pediat-

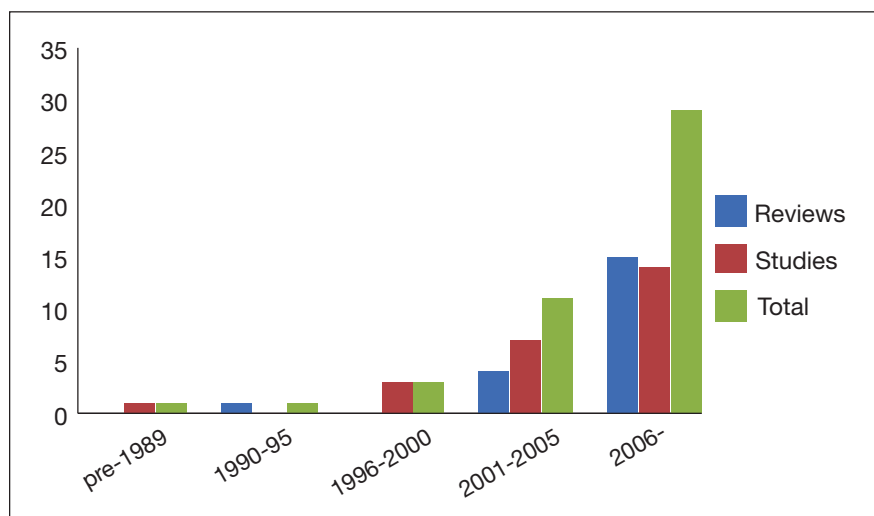


Figure 2. Transition literature in type 1 diabetes: studies and reviews.

ric unit and home at the same time and follow-up with a new diabetes team in their new city, or should the transition occur closer to home?

Studies of Transition Outcomes

Transition of chronic childhood disease conditions is a relatively new field, and research to guide practice is severely lacking. The available literature tends to have focused most, but not all, of its attention on two conditions: type 1 diabetes and cystic fibrosis (CF). These two disorders account for 60 of 96 articles on transition from pediatric to adult care found in a systematic review of the literature published between 2000 and 2010. A breakdown of the research in diabetes transition care by year and type of publication (original study or review article) is shown in Figure 2. The reasons for the increasing attention in type 1 diabetes and CF are quite different. In type 1 diabetes, transition is important in the need to maintain ongoing excellent control during the difficult stages of late adolescence and early adulthood. In CF, the attention to transition has been necessitated by the enormous increase in longevity brought about by modern therapy.

There are two types of studies reported in the transition literature. First are those in which the outcomes of the transition or transfer process are described, with most addressing loss to follow-up and ongoing metabolic control. Second are studies that are mainly observational, consisting of case series or cross-sectional studies reporting the impact of different transition care models such as anticipatory guidance or transition care coordinators on diabetes-related health outcomes.

Table 1 summarizes the main studies of outcome. In general, when there is no formal transition program in place, a “loss to follow-up” rate of > 20–25% can be expected in the 2–4 years after discharge from the pediatric center.^{6–12} One study from Finland showed a significant improvement in metabolic control after transition to adult care, although other studies have failed to confirm this.⁶ Of note, in a recent health services study of 1,507 adolescents with diabetes undergoing a transition of care at 18 years of age in the Province of Ontario, Canada, we reported two important findings: there was a small but significant increased risk of hospitalization for

Table 1. Studies of Outcome of Transition to Adult Care in Adolescents With Type 1 Diabetes

Outcome study	Design	<i>n</i>	Duration of follow-up (years)	Outcome measure	Results	Comments
Salmi et al., 1986, Finland ⁶	Prospective cohort study	61	1	A1C pre- and post-transfer	Improved 11.2 ± 2.2 to 9.8 ± 1.7% (<i>P</i> < 0.001)	Small, selected cohort
Frank, 1996, Canada ⁷	Retrospective cohort study	41	3–4	Loss to follow-up and diabetes-related hospitalizations	24% loss to follow-up and increased hospitalizations (60 vs. 19%, <i>P</i> < 0.05)	Small cohort with varied follow-up time between patients
Pacaud et al., 1996 Montreal, Canada ⁸	Cross-sectional survey	135	2–4	Loss to follow-up	13% lost to medical follow-up for diabetes care	Poor response rate (36%); ascertainment of outcomes based on self-reports
Pacaud and Yale, 2005, Calgary, Canada ⁹	Cross-sectional survey	81	2–4	Loss to follow-up; comparison of two differing health care models	14% lost to medical follow-up for diabetes care; no difference in outcome between two differing health care models (i.e., Montreal vs. Calgary) (significance not provided)	Poor response rate (53%); ascertainment of outcomes based on self-reports
Orr et al., 1996, United States ¹⁰	Prospective cohort study	82	1	A1C	No change in A1C (9.9 ± 1.8% vs. 10.2 ± 1.9%; <i>P</i> = 0.125)	Only clinic attenders included
Busse et al., 1997, Germany ¹¹	Retrospective	101	1–3	Clinic visits and A1C	Decrease in clinic attendance (8.5 ± 2.3 visits/year vs. 6.7 ± 3.2 visits/year, <i>P</i> < 0.001); No change in A1C (8.5 ± 1.5% vs. 8.3 ± 1.6%, <i>P</i> = 0.441)	Small cohort
Nakhla et al., 2009, Canada ¹²	Retrospective cohort study; population-based health administrative data	1,507	2	Hospitalizations	Small but significant increase (7.6 to 9.5 per 100 patient-years, <i>P</i> = 0.03)	Did not distinguish between type 1 and type 2 diabetes

diabetic ketoacidosis (DKA) in the 2 years after transition. Also, female sex, lower socioeconomic status, poorer local medical resources, and previous hospitalizations for DKA were significant predictors of post-transition hospitalizations.

Adolescents leaving their pediatric team and starting afresh with a new physician and new team were more likely to be hospitalized for DKA than those whose adult team included some of the members of their pediatric team.¹² This suggests that some conti-

nunity of care should be a consideration during transition.

Table 2 summarizes the major intervention studies.^{4,13–17} In essence, interventions aimed at decreasing loss to follow-up achieve this aim. However, no studies show a better outcome in terms of metabolic control, psychosocial adjustment, complication rates, or other metabolic or medical indicators. The major approaches have included anticipatory guidance, transition care coordination, and young adult clinics. Virtually all interventions include a strong education or

psychoeducation component with the opportunity to meet with members of the adult diabetes team.

Summary and Conclusions

Although often hotly debated, the issue of transition to adult diabetes care has received scant attention in the medical literature. Findings from observational studies indicate that, unless specific programs are in place, there is a significant loss to follow-up; that there tends to be more DKA episodes after transition, although metabolic control outcomes are quite variable; and that

Table 2. Intervention Studies of Transition to Adult Care in Type 1 Diabetes

Interventions	Design	n; duration	Method of transition	Outcome measure	Results and comments
Frank, 2002, Canada ¹³	Case series	76; 2–4 years	Anticipatory guidance; formal and informal workshops	Loss to follow-up	7% loss; significant improvement compared to 1989 cohort
Kipps et al., 2002, United Kingdom ⁴	Retrospective cohort study	229; 2 years	Four groups of post-transition care	Follow-up and A1C	Significant decrease in attendance (98 vs. 61%, $P < 0.001$); greatest declines in those directly transferred to adult clinic or young adult clinic; no change in A1C; not randomized
Johnston et al., 2006, United Kingdom ¹⁴	Case series	33; 15–18 months	Young adult clinics	Attendance	18% loss to follow-up; twice attendance to Saturday young adult clinic (NS)
Vidal et al., 2001, Spain ¹⁵	Case series	72; 1 year	Anticipatory guidance and meeting with adult staff	A1C; knowledge and self-adjustment	All improved; A1C results not given ($P < 0.001$); improved diabetes knowledge on self-management ($P < 0.001$); no comparison group
Holmes-Walker et al., 2007, United Kingdom ¹⁶	Retrospective	181; 5 years	Transition coordinator; after-hours phone	A1C and DKA	A1C lower by 0.13% ($P < 0.001$); no comparison group
Van Wallegem et al., 2006, Canada ¹⁷	Retrospective cohort study	101; 1 year	Transition coordinator; education groups	Number of physician and nurse visits	Increased number of visits in those directly referred to program at 18 years of age and in those enrolled in program after the age of 18 years (significance not provided)

little is known about factors that may support or hinder the transition process. The intervention studies suggest that, with careful support and attention, these negative outcomes can be mitigated. Successful interventions include anticipatory guidance starting early in the course of diabetes, care ambassadors, and young adult diabetes clinics incorporating pediatric and adolescent health care professionals.

The gaps in our knowledge of the transition care process remain considerable; for example, quantitative data about when and where to transition are essential, as is the impact of different transition models on metabolic control, diabetes-related hospitalization rates, and long-term complications. More qualitative outcome measures ought to assess quality-of-life issues (e.g., anxiety/depression, fear of hypoglycemia, and the impact of fear on compliance). The different approaches to transition ought to be studied in

terms of their impacts on education level, job performance, interpersonal relationships, and driving. There can be no doubt that carefully performed studies have the opportunity to shed important light on the issues at hand and to replace the uniform protocols currently used in transition programs to more individualized approaches.

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