

## REVIEW

# Transitions in the care of children and youth with Type 1 diabetes



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### Practice Points

- Infants and preschoolers have an increased risk of experiencing severe hypoglycemia, as such glycemic targets are higher in this group compared with older children.
- Schoolaged children may gradually assume more of their daily diabetes management; however, parental supervision and involvement remains essential.
- Early initiation of independent self-management is associated with poorer glycemic control.
- Glycemic control deteriorates during adolescence due to the physiological and psychological changes associated with this stage of development.
- Parental involvement in diabetes management during adolescence is important and is associated with better diabetes outcomes.
- Adolescents with Type 1 diabetes are at an increased risk of having a psychiatric disorder, notably major depressive disorder.
- Preparation for the transition to adult care should begin in early adolescence and involve the whole family unit.
- The transition to adult diabetes care is associated with a deterioration in medical supervision and an increased risk of diabetes-related hospitalizations.
- There is no consensus on the optimal methods to transition patients to adult care.
- The literature on transition care is sparse, in particular there is a paucity of research evaluating different transition care models and their impact on clinical outcomes.
- Strategies such as a young adult clinic, a transition care coordinator and an educational transition program may improve outcomes during the transition process.

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**SUMMARY** Type 1 diabetes (T1D) is one of the most common chronic diseases of childhood. The physiological, psychological, social and emotional changes that occur as a child develops present unique challenges in the management of T1D. This article reviews the management of T1D within the following developmental transition stages, with a focus on the transition to adult care: preschool to schoolaged; schoolaged to adolescence; and the transition to adulthood.

Type 1 diabetes (T1D) is one of the most common chronic diseases of childhood with important morbidity and mortality [1,2]. The incidence of T1D is on the rise worldwide, with an average annual increase that is more rapid in preschoolers (5.4% [4.8–6.1%]) compared with older children (2.9% [2.5–3.3%]) [3,4]. The physiological, psychological, social and emotional changes that occur as a child develops present unique challenges in the management of T1D. Overall care of children and youth with T1D must, of necessity, pay careful attention to the child's age and developmental stage, as well as involve the entire family unit. The following review summarizes diabetes management issues that are unique to the following developmental transition phases, with a focus on the transition to adolescence and adulthood:

- Preschool to schoolaged
- Schoolaged to adolescence
- Transition to adulthood

For specific management recommendations the reader is encouraged to refer to the referenced diabetes guidelines [5,6].

### Preschool to schoolaged

#### ▪ Infants & preschoolers

Children in this stage of development present unique challenges to their families and healthcare providers. Parents and caregivers carry the burden of daily diabetes management. Infant's and preschooler's often unpredictable eating habits and activity levels may result in variations in day-to-day insulin requirements, leading to difficulties in achieving optimal glycemic control while minimizing the risk of hypoglycemia. With respect to hypoglycemia in this age group, three issues need to be considered. First, younger children with T1D do not always exhibit the typical catecholamine response and are not able to communicate the sensations of hypoglycemia; as such they are at the greatest risk of experiencing severe hypoglycemia (i.e., seizures and coma) than older children [7]. Second, as the brain is still developing in this age group,

there are potentially significant neurodevelopmental consequences of repeated hypoglycemic episodes including the development of subtle neuropsychological or intellectual impairments [8,9]. Third, as infants and toddlers are unable to express the symptoms of hypoglycemia, parents have difficulties in identifying whether behavioral changes, such as oppositional behavior or temper tantrums are due to a hypoglycemic event. Because of these risks of hypoglycemia, recommended glycemic targets are higher (6–12 mmol/l) as compared with older children. This stage is particularly challenging for parents as they struggle with their fear of hypoglycemia while at the same time remain anxious about the risk of long-term complications [10,11]. An experienced and supportive diabetes healthcare team can go a long way in alleviating the family stresses during this potentially precarious stage of development.

#### ▪ Schoolaged

As children enter the schoolage period, they will spend more and more time away from their parents and, therefore, will gradually assume more of their daily diabetes management. Ongoing adult support and supervision remains essential, as poorer glycemic control in this age group has been associated with too early initiation of independent self-management [12,13]. Furthermore, parent-child conflict, which is associated with decreased treatment adherence and poor glycemic control, tends to begin during this period [14]. Much research has been devoted to parenting styles and its effects on treatment adherence and glycemic control. Notably, Davis *et al.* found that among 4–10 year old children with T1D, greater parental warmth (characterized as support and affection) was associated with improved treatment adherence and that parental restrictiveness was associated with worse glycemic control [15]. The authors concluded that greater parental warmth leads to a reduction in family conflict and/or an increase in family cohesiveness. In addition, research has shown that an 'authoritative' style of parenting, was related to higher levels of treatment adherence

by the child and to better glycemic control [15]. This style of parenting involves being engaged with the child with warmth, while setting limits and expecting high levels of maturity and independence with low levels of coerciveness. Thus, responsibility for diabetes management should be shared between children and their parents [6].

Schoolaged children will rely more on others outside of the home, including teachers and, where available, school nurses and other school personnel, to help with their care. Because children spend a great deal of their daytime hours in school, levels of support and care adjusted to their age and development are important for the optimal management of T1D in the school setting. For example, recent guidelines have been published in Quebec, Canada on the management of children with T1D in the school setting. The guidelines describe the responsibilities of parents, school nurses and other educators involved in the care of children, as well as the children themselves [101].

Children in this age group may begin to feel different: regular school attendance and participation in school activities are important factors in the development of normal peer relationships [6]. Nurses, teachers and other personnel who are trained to help monitor and support the needs of children with T1D have the potential to make a significant difference in ensuring that the child's health, school performance and social development are not compromised. Data suggest that school attendance of children with T1D is very similar to that of their nondiabetic siblings [16].

## Schoolaged to adolescence

### ■ Adolescence

Adolescence is a vulnerable transition period during which there is a focus on establishing his/her own personal identity and sense of autonomy, as well as making future-oriented (e.g., vocational and educational) decisions. For those with diabetes, this period is further complicated by the daily demands of a chronic disease, as the adolescent moves from parental dependency to increased autonomy. In addition, adolescence is a stage that is characterized by tremendous physical, social and psychological growth that makes optimizing glycemic control a challenge. The deterioration in glycemic control that occurs during adolescence was notably demonstrated in the DCCT: the adolescent subgroup, in both the conventional and intensive treatment arms, had an A1c approximately 1%

higher compared with the adult cohort [17]. This worsening metabolic control is probably due to the complex interaction between the physiologic and psychosocial changes that are unique to adolescence. Physiologic changes include an increase in insulin resistance with a resultant increase in insulin needs [18]. Psychosocial factors common in adolescence include decreased adherence to diabetes management tasks [19], decreased clinic attendance [20], an increased risk of psychiatric disorders [21] and involvement in hazardous and risk-taking behaviors.

As youth mature, their responsibility in diabetes management increases, however, adherence tends to decrease over this same time period [22,23]. Factors that interfere with an adolescent's ability to optimally manage their diabetes include decreased parental involvement, the need to adapt to peers norms, which may be in conflict with optimal diabetes management, as well as family conflict [24]. Although adolescents can be mainly responsible for the daily management of their diabetes, minimal or no adult supervision results in poor glycemic control [25,26]. In a cross-sectional study of 89 youth with diabetes aged 10–15 years, decreased parental involvement resulted in decreased adherence to blood glucose monitoring resulting in poorer glycemic control [25]. Another cross-sectional study by Wysocki *et al.* demonstrated that excessive self-care autonomy increased with age and was associated with decreased treatment adherence, less diabetes knowledge, increased history of hospitalizations and poorer glycemic control [26]. The authors concluded that families who are able to maintain parental involvement in diabetes management during adolescence are more likely to have better diabetes outcomes [26]. The challenge is to find an appropriate degree of parental involvement without generating conflict within the family. Several studies have demonstrated that diabetes-specific conflict within families is associated with decreased treatment adherence and poor glycemic control [27,28]. The diabetes care team should help facilitate and support the gradual transition from parental dependency to cooperative care with the adolescent, while minimizing conflict [24]. Furthermore, decision-making should be increasingly directed towards the adolescent while retaining the trust and support of parents [24]. Preparation for the transition to adult care should begin early in adolescence and involve both the adolescent and his/her parents [6].

Other issues unique to adolescence are outlined in the following paragraphs.

**Risk-taking behavior:** youth with diabetes, similar to their nondiabetic peers, may engage in risky behaviors, such as alcohol and tobacco use, as well as unprotected sexual intercourse. There is no evidence to suggest that youth with T1D are more likely to take part in these risk-taking behaviors [29,30]; however, the consequences of such are important in those adolescents with T1D. Alcohol use is a well-known risk factor for severe hypoglycemia. After drinking moderate amounts of alcohol, adolescents with T1D may become hypoglycemia unaware, increasing the risk of severe hypoglycemia. Caregivers should encourage adolescents to refrain from alcohol use; however, they should still provide the adolescent with a practical approach to alcohol intake. Steps such as having carbohydrates while drinking, maintaining good hydration, measuring blood glucose levels before bedtime and having carbohydrates before sleep reduce the risk of hypoglycemia [24].

Smoking among youth with T1D is prevalent and is associated with higher A1c levels, poorer cardiovascular risk profiles and increased risk of microalbuminuria when compared with nonsmokers [31]. In a sample of 27,561 youth aged 15–20 years with T1D, smoking was associated with higher A1c, triglyceride and total cholesterol levels, and lower levels of high-density lipoprotein cholesterol compared with nonsmokers [31]. In a cross-sectional study of youth, aged 10–22 years with T1D and Type 2 diabetes, Reynolds *et al.* found that smoking was associated with a higher odds of physical inactivity [30]. Smoking prevention and cessation should be advocated throughout childhood and adolescence to prevent the development of cardiovascular disease.

Many adolescents experiment with sexual behavior. Adolescents with T1D may be at increased risk for unplanned pregnancy and sexually transmitted diseases. One study of adolescents with T1D found that only half of those who were sexually active used condoms or other forms of birth control (compared with 61% in the general population) [32]. Regular counseling regarding contraception and sexual health should be an integral part of diabetes care [24]. Adolescent girls should receive counseling regarding the importance of a planned pregnancy and the fetal complications associated with poor glycemic control at time of conception and throughout the pregnancy [24].

### Psychiatric issues

Psychiatric disorders and behavioral problems are frequent in patients with T1D [21,33,34] and contribute to decreased treatment adherence [35], poor glycemic control [35,36] and an increased risk of diabetes-related complications, including diabetic ketoacidosis [36–39]. Adolescents with T1D have a two- to three-fold increased risk of psychiatric disorders compared with those without diabetes [40–43]. The most common psychiatric comorbidity seen in this population is major depressive disorder. The prevalence of depression among youth with T1D is estimated to be between 10 and 27% [41,42,44]. Risk factors associated with depression include female gender [36,41], family stress or dysfunction [44], and maternal depression [42]. In addition, studies suggest that psychiatric disorders, including depression during adolescence, persist into adulthood and predict persistently poor glycemic control [38]. Notably, this was demonstrated in an 11-year longitudinal study of young adults, originally aged 17–25 years that showed an increase in the prevalence of psychiatric conditions from 16 to 28%, which is 40% higher than the general population prevalence [38]. Furthermore, an 8-year longitudinal cohort study of adolescents followed into young adulthood (20–28 years of age) found that behavioral problems at baseline were a predictor of poor glycemic control in young adulthood [34]. Given the prevalence of depression and its effect on metabolic control, both the Canadian and American Diabetes Association recommend routine depression screening for children and adolescents with T1D [5,6].

High rates of disordered eating have also been reported in youth with T1D. A total of 10% of adolescent females with T1D meet the Diagnostic and Statistical Manual of Mental Disorders (4th Edition) criteria for eating disorders compared with 4% of their age-matched controls without diabetes [45]. According to the Diagnostic and Statistical Manual of Mental Disorders (4th Edition), the two eating disorders most often associated with T1D are bulimia nervosa and eating disorders not otherwise specified. Three aspects of T1D may contribute to the development of an eating disorder [46]: first, the acute weight gain associated with the initiation of insulin or improvement in metabolic control; second, dietary restraint required as part of the nutritional management of diabetes [47]; and third, deliberate insulin omission as a unique and

readily available way to control weight through induced hyperglycemia and glycosuria [46]. Insulin omission results in suboptimal glycemic control and an increased risk for earlier microvascular complications including retinopathy and nephropathy, as well as mortality [21].

The identification and treatment of psychiatric disorders is a crucial part in the management of diabetes. Pediatricians are in a unique position to identify symptoms early and to institute prompt treatment.

### Transition to adulthood

The transition to adult care occurs during a critical and vulnerable period for those with T1D. Successful transition care for adolescents with T1D is particularly important because regular medical supervision, screening for microvascular complications and optimizing glycemic control are essential in reducing the onset and progression of diabetes-related complications. However, during this period, adolescents are at serious risk of being lost to medical supervision [48–51]. It is generally agreed that all young adults should receive care that is not only appropriate for age and the stage of development, but that also gradually shifts the decision-making from the parent to the adolescent–parent unit and finally to the young adult [52], that is from a family-centered care model to a patient-centered one. Traditionally, the pediatric care model tends to be more protective, authoritarian and parent-oriented than that in adult care, which focuses almost exclusively on the disease with little psychological support and assumes the patient to be fully autonomous [53].

The key challenge for transitional healthcare services is bridging the differing cultures of pediatric, adolescent and adult healthcare. Transition care is defined as the ‘purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems. It is a multidisciplinary process that addresses the medical, psychological, educational and vocational needs of adolescents as they move from pediatric to adult services’ [53]. Transfer of care is just an event and only one component of transition care. Although the need to address young adults’ unique healthcare needs is recognized, there is no consensus on the optimal methods to transition patients to adult care, particularly for those with diabetes mellitus. Literature on transition care remains sparse

and there continues to be a paucity of research on the magnitude of the problem, as well as research evaluating different transition care models and their impact on clinical outcomes. However, the existing literature do suggest that as a medical community we need to improve how and when we transition patients to adult care. This has been demonstrated in several qualitative studies where patients report a sense of abandonment and sadness with the loss of the patient–provider relationship, and many find the transfer to adult care to be a negative experience [48,49,54].

The transition literature mainly consists of two types of studies: first, those studies that report on the outcomes of transition; and second, those that report on the impact of different transition care models on outcomes, most of which are mainly descriptive, including case series and cross-sectional studies.

### Outcomes of transition care

**Table 1** summarizes the main studies examining the outcomes of transition care. The outcomes that have been examined include adherence to medical visits, metabolic control and acute diabetes-related complications. With respect to medical supervision, two cross-sectional studies [48,49] and two retrospective cohort studies [50,55] found that 11–40% of patients fail to follow-up in the adult diabetes healthcare system. The literature on metabolic control is conflicting with one study from Finland suggesting that metabolic control improves with transition [56], while another demonstrated no change [55]. In a population-based study of 1507 adolescents, we have previously shown a modest but significant increase in diabetes mellitus-related hospitalizations following the transfer to adult care [57]. Significant risk factors include female gender, lower socioeconomic status, previous diabetes-related hospitalizations and living in areas of low pediatric physician supply [57]. We also found that adolescents that were transferred to a new diabetes team had an increased risk of hospitalizations compared with those whose adult team included some members of the pediatric team. Our findings suggest that some continuity with the pediatric team should be considered in implementing a transition program.

### Studies evaluating transition care models

Multiple methods of transition care in diabetes have been described; however, the outcomes literature is sparse, consisting predominantly of

Table 1. Outcomes of the transition to adult care.

Author (year); Location	Study design	n	Follow-up (years)	Primary outcome	Results	Limitations	Ref.
Salmi <i>et al.</i> (1986); Finland	Prospective cohort study	49	1	A1c pre- and post-transfer	Improved $11.2 \pm 2.2$ to $9.8 \pm 1.7\%$ ( $p < 0.001$ )	Small sample size	[56]
Frank (1996); Canada	Retrospective cohort study	41	3–4	Loss to follow-up	24% lost to follow-up	Small cohort with variable follow-up time between patients	[50]
Pacaud <i>et al.</i> (1996); Montreal, Canada	Cross-sectional survey	135	1–5	Loss to follow-up	13% lost to medical follow-up for diabetes care	Poor response rate (36%) Ascertainment of outcomes based on self-reports	[48]
Pacaud <i>et al.</i> (2005); Calgary, Canada	Cross-sectional survey	81	1–6	Loss to follow-up Comparison of two differing healthcare models (i.e., Montreal vs Calgary)	14% lost to medical follow-up for diabetes care No difference in outcome between two differing healthcare models (significance not provided)	Poor response rate (53%) Ascertainment of outcomes based on self-reports	[49]
Orr <i>et al.</i> (1996); USA	Prospective cohort study	82	1	A1c	No change in A1c ( $9.9 \pm 1.8\%$ vs $10.2 \pm 1.9\%$ ; $p = 0.125$ )	Only clinic attendees included	[62]
Busse <i>et al.</i> (1997); Germany	Retrospective cohort study	101	1–8	Mean clinic visits and A1c 1 year pre- and post-transfer	Decrease in clinic attendance ( $8.5 \pm 2.3$ vs $6.7 \pm 3.2$ visits/year; $p < 0.001$ ) No change in A1c ( $8.5 \pm 1.5$ vs $8.3 \pm 1.6\%$ ; $p = 0.441$ )	Small cohort Outcomes extracted from self-reports Variable follow-up times between subjects	[55]
Nakhla <i>et al.</i> (2009); Canada	Retrospective population-based cohort study	1507	2	Diabetes mellitus-related hospitalization rates comparison 2 years pre- and post-transfer	Small but significant increase ( $7.6$ – $9.5/100$ patient-years; $p = 0.03$ )	Did not distinguish between Type 1 and 2 diabetes	[57]

descriptions of program characteristics with little attention to robust research design and analysis (Table 2). Methods of transition care that have been evaluated include a young adult transition clinic attended by both adult and pediatric physicians, a transition coordinator who aids in the transition process and anticipatory educational guidance. We will highlight here the pertinent findings from three of these studies. First, a retrospective cohort study conducted in the UK of 229 young adults (mean age: 22.1 years; range: 18.2–28.7 years) evaluated different transition care models within four health districts in Oxford (UK) [58]: direct transfer to an adult clinic; transfer to a young adult clinic in a different hospital; transfer to a young adult clinic within the same hospital where pediatric care was obtained with introductions to the adult physician prior to transfer; and transfer to an adolescent clinic jointly run by pediatric and adult physicians. Overall, the proportion of subjects attending clinic at least twice per year, dropped from 98% in the 2 years pretransfer to 61% in the 2 years post-transfer ( $n = 96$ ;  $p < 0.001$ ). The greatest declines in clinic attendance were noted among the subjects that were either transferred to a young adult clinic in a different hospital (district two) or among those directly transferred to adult care (district one). In addition, the group that was directly transferred to adult care was the most dissatisfied with transfer compared with the other three groups (47% of subjects compared with 12% district two, 4% district three and 12% district four;  $p = 0.004$ ). No interdistrict difference in post-transfer A1c levels was seen; however, this was only measured among patients still attending hospital clinics. The authors suggest that transition to a young adult clinic is preferable than to direct transfer to an adult clinic. In addition, meeting with staff from the adult team prior to transfer may result in improved outcomes.

Second, Frank conducted a case-series evaluating a transition education program consisting of workshops that provided anticipatory guidance on the transfer to adult care, as well as support for both parents and teens during the transition process [59]. Results from the program evaluation indicate that with the implementation of the program, the proportion of patients lost to follow-up was 7%, 2–4 years following the transfer to adult care. This was an improvement compared with historical control evaluated in an initial 1989 study (24% lost to follow-up

following transfer) [59]. Third, a retrospective cohort study with historical controls was conducted by Van Walleggem *et al.* to evaluate the effect of a transition care coordinator on diabetes care visit attendance following the transition to adult care [60]. The coordinator identified and facilitated access to appropriate adult diabetes care services in the community for young adults with T1D (aged 18–25 years). The study cohort consisted of two groups: patients referred to the program at age 18 years directly from the pediatric program ('younger group'), and patients (aged 19–25 years) who had already graduated from pediatric care prior to the implementation of the program, but later enrolled in the program ('older group'). Among the younger age group, 11% were lost to follow-up compared with 40% in the older group, who did not have access to the navigator at time of transfer. This is the only study within the diabetes literature that has specifically and systematically assessed the outcomes of its transition program. Strategies that may improve clinic attendance rates include implementing an educational transition program, a transition coordinator to aid in the transition process and a young adult transition clinic attended by both adult and pediatric physicians. However, a major theme in the literature is the lack of robust randomized controlled trials evaluating the best methods for transitioning care and how this translates to improving diabetes-related clinical outcomes.

Of interest is the issue of when to transfer patients to adult care. Despite recommendations that the timing of transfer should be dependent upon patient maturity, medical stability and readiness, rather than by chronological age; many institutions mandate transfer at a specific age (usually 18 years in the USA, but as young as 12 years of age in some countries). One study in the nephrology literature examined the association of age of transfer on renal graft failure. Foster *et al.* conducted a retrospective cohort study of 440 kidney recipients who had been transferred to adult care [61]. The authors found that younger age of transfer (<21 years) was associated with a higher rate of graft failure compared with older age of transfer (>21 years). The authors postulate that the difficulties associated with transfer have less to do with the method of transition but with an individual's readiness to transition and their maturity level, which cannot be sped up with an effective transition program.

Table 2. Evaluation of transition care models.

Author (year); Location	Study design (n)	Follow-up	Method of transition	Outcome measure	Results and limitations	Ref.
Frank (2002); Canada	Case series (76)	2–4 years	Anticipatory guidance: formal and informal workshops	Loss to follow-up	7% lost to follow-up – significant improvement compared with 1989 cohort. Small sample size	[59]
Kipps <i>et al.</i> (2002); UK	Retrospective cohort study (229)	2 years	Four groups of transition care	Proportion of patients with regular clinic attendance	Significant decrease in attendance (98 vs 61%; $p < 0.001$ ); greatest declines in those directly transferred to adult clinic or young adult clinic	[58]
Johnston <i>et al.</i> (2006); UK	Case series (33)	15–18 months	Young adult clinics (ages 16–25 years)	Proportion of patients attending clinic regularly; compared between adult and young adult clinics	Proportion with regular clinic attendance: 20% adult clinic; 50% young adult clinic. Participant characteristics not compared between groups	[63]
Vidal <i>et al.</i> (2004); Spain	Case series (72)	1 year	Anticipatory guidance and meet with adult staff monthly 3–6 months prior to transfer	A1c; diabetes knowledge	All improved; A1c results not given ( $p < 0.001$ ); improved diabetes knowledge on self-management ( $p < 0.001$ ). No control group	[64]
Holmes-Walker <i>et al.</i> (2007); UK	Case series (191)	5 years	Transition coordinator; after hours phone support	A1c	A1c lower by 0.13% ( $p < 0.001$ ). No control group	[65]
Van Wallegghem <i>et al.</i> (2006); Canada	Retrospective cohort study (165)	1 years	Transition coordinator and education groups for young adults ages 17–25 years	Patients with no medical supervision compared: 'older group' 1 year pre- and 1 year post-recruitment and 'younger group' 1 year pre- and 1 year post-transfer	Increased proportion of patients (40%) lost to follow-up in older group compared with younger group (11%)	[60]



## Conclusion

The environment in which children and youth find themselves is increasingly complex, starting in the young with parent-guided care and continuing through a series of development transitions to independent self-management in adulthood. There can be no doubt that this process is best facilitated in the context of care by a multidisciplinary healthcare team, experienced not only in diabetes but, as importantly, in the stages of development and impact of the social determinants of health. In addition to a multidisciplinary team, other strategies that can support patients and their families navigate these transitions include: diabetes camp, in which children meet others with diabetes and learn to self-manage their diabetes in healthy ways; and diabetes re-education for families with an emphasis on effective problem-solving and self-management skills, which are increasingly directed to the patient as they mature. The final transition from the pediatric to adult healthcare team remains the focus of intense attention, but the data to support any one approach remain elusive.

## Future perspective

Among the developmental transitions that a child with T1D experiences, the transition to adult care is one of the most difficult, with little evidence-based guidance on how best to navigate this important step. Over the next decade, there will be an emergence of evidence-based approaches to guide best practices on transitioning patients. Furthermore, as interest in the transition to adult care increases, knowledge of the medical and psychosocial issues unique to young adults with T1D, will increase among adult providers.

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