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Transfer from pediatric to adult health care: effects on diabetes outcomes

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Abstract

The transfer from pediatric to adult diabetes health care for emerging adults with type 1 diabetes (T1D) has received increasing attention in the literature. This review analyzes the effect of this health care transfer on the outcomes of diabetes care visit attendance, glycemic control, and acute diabetes-related complications, and assesses the methodological strength of the studies reporting observational and interventional data. Observational studies, often limited by incomplete data, report a decline in diabetes care visits but an improvement or no change in hemoglobin A1c (HbA1c) after transfer to adult care. Results from studies reporting a transition intervention are restricted by lack of appropriate control groups and the collection of data both before and after transfer of care. Very few methodologically strong studies are available to guide clinicians with the transition from pediatric to adult care, and these shortcomings should be addressed in future studies designed to facilitate and improve the care of emerging adults with T1D.

Keywords

diabetes mellitus; transition to adult care; young adult

A significant life event for youth with chronic medical conditions is the transfer from pediatric to adult health care (1). The terms 'transition' and 'transfer' are often used interchangeably in everyday conversation to denote this event, yet their definitions are not the same. Health care transition is the process that prepares youth for the actual transfer of medical care (2). The transfer from pediatric to adult care often coincides with a stage of life known as emerging adulthood, which is between ages 18–25 (3).

The transition to adult care for emerging adults with type 1 diabetes (T1D) has received increasing attention (4–7), and a number of review articles have addressed the topic. A common theme among these review articles is an association of transfer to adult care with

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poor glycemic control and loss of clinical follow-up (4, 8, 9). However, the methodological strength of the studies examining the effect of transfer on glycemic control and diabetes care visit attendance is not assessed in these review articles. The 2011 position statement, 'Diabetes Care for Emerging Adults: Recommendations for Transition From Pediatric to Adult Diabetes Care Systems,' acknowledges the limited empirical evidence and the majority of recommendations to guide health care providers are based on expert consensus or clinical experience (10).

The purpose of this literature review is to evaluate the empirical evidence on the effect of the transfer of care from pediatric to adult providers on diabetes outcomes. The outcomes of glycemic control, diabetes care visit attendance, and acute complication rates have been selected as these are associated with morbidity and mortality (11). This review explicitly focuses on the empirical evidence with the aims of examining the methodological strength of the studies and identifying links between the transfer from pediatric care settings to adult care settings and diabetes outcomes. This assessment of the empirical evidence may provide future direction for both patient care and research that can advance this field of inquiry so that planning strategies can be based on sound evidence.

Methods

A search of the literature was performed with PubMed and Embase using search query terms of T1D, transition, transfer, adolescents, and emerging adults. Additional publications were identified by examination of articles' references. Studies published prior to May 2013 were included if they reported measures of hemoglobin A1c (HbA1c), diabetes care visit attendance, and/or complication rates in the adult health care setting recently after transfer to adult care. Studies that relied on patients' report of HbA1c, clinic attendance, and/or complications were excluded. Eighteen publications were identified by this method. These observational and interventional studies utilize a variety of methods to assess the diabetes outcomes associated with the transition from pediatric to adult care, each of which will be discussed below.

The first section of the results describes 12 observational studies that provide data on diabetes outcomes before and after the transfer of care. The second section reviews eight studies (two of which are also included in the first section) that evaluate the effects of transition interventions on diabetes outcomes after the transfer to adult care.

Results

Observational studies

Observational studies have been the most common methodology employed to date to evaluate diabetes outcomes associated with the transfer from pediatric to adult care. These studies use simple prepost designs, by comparing HbA1c (shown in Table 1), diabetes care visit attendance and/or acute complication rates in the pediatric and adult clinics. While the pediatric care settings in these studies are university-based or regional pediatric diabetes clinics, the adult care settings vary and include dedicated young adult diabetes clinics, university hospital system diabetes clinics, private specialists and general practitioners.

These studies are limited in the conclusions that can be drawn from them because they do not have a comparison group. Without a comparison group, any observed differences between pediatric and adult care could be a function of the type of care chosen, the process of changing care, and/or pubertal and psychosocial maturation.

Hemoglobin A1c—Eight studies examined HbA1c before and after transfer from pediatric to adult care (12–19), and five of these reported that HbA1c significantly improved in adult care (12–16). The first report of improved HbA1c was in 1986 in a Finnish study of 49 patients comparing mean HbA1c 1 yr before and 1 yr after transfer within a university hospital-based system (12). The improvement in glycemic control after 1 yr in the adult clinic remained significant regardless of diabetes duration. In an Italian study reporting the results of a structured transition method involving both pediatric and adult diabetes providers at a university hospital, mean HbA1c of 64 patients significantly improved after 1 yr in the adult clinic (13). In a third study, 33 patients in the UK were transferred from a pediatric diabetes clinic to either a young adult diabetes clinic or a general adult diabetes clinic within the same hospital system (14). Although the authors did not conduct a statistical comparison of HbA1c before and after transfer, HbA1c improved after transfer based on our statistical test of the provided data. While the transition methods varied in these three studies, they all had centers in which the pediatric and adult clinics were affiliated, which may have facilitated the transition of care.

An improvement in HbA1c was also identified in two reports in which patients transferred from a single pediatric clinic to multiple adult clinics (15, 16). In a Swedish study, patients from the same pediatric clinic were referred to six different adult clinics (15). The study did not examine transfer from pediatric to adult care *per se* but compared HbA1c at age 18, when presumably the majority of participants were in pediatric care, to age 24, when presumably the majority of participants were in adult care. Statistical analysis showed that HbA1c significantly improved from age 18 to 24 for females but not males. However, females had a significantly higher HbA1c in the pediatric clinic compared with males, implying more potential for improvement. It must be noted that the comparison of HbA1c over a 6-yr span captures more than just the transfer from pediatric to adult diabetes care. The physical and psychosocial maturation from age 18 to 24 are likely contributors to the observed changes in glycemic control. A German report surveying 99 patients about their medical care after transfer from a pediatric diabetes clinic to a variety of adult providers noted a slight improvement in glycemic control, but HbA1c was only available for 34 of the 99 persons in the study 1 yr after transfer of care (16). Because HbA1c data was not provided for this specific subgroup prior to transfer, a statistical comparison could not be performed.

The remaining three studies detected no change in HbA1c from before to after transfer of care (17–19). For 77 patients in Indiana transitioning to adult care within the same university medical center, HbA1c did not statistically change (17). No difference in glycemic control was observed in a German study of 44 patients transitioning from a university-based pediatric clinic to an array of adult providers (18). This is also likely the case in a UK study comparing four regions with different methods of transfer, but a statistical comparison was

not made between the mean pediatric HbA1c for all four regions and the mean adult HbA1c for those still attending hospital clinics in all four regions (19).

In contrast to the above studies, two recent studies examined the association between HbA1c of emerging adult patients and the type of provider (20, 21). In a prospective longitudinal study of 119 adolescents in Pennsylvania, early transfer from pediatric to adult care was associated with worse glycemic control (20). Patients who had transferred to adult care prior to their senior year in high school had significantly higher HbA1c than their peers who remained in pediatric care 1 yr after high school graduation. The HbA1c of the group of patients who transitioned from pediatric care in their senior year of high school to adult care 1 yr later did not significantly differ from those who remained in pediatric care over the same time period. The second study longitudinally evaluated data from 185 patients with T1D from a baseline visit (average age 15.9 yr) to a follow-up study visit (average age 20.5 yr). At the follow-up study visit, 57% of the patients had transferred to adult diabetes care providers. The study found that being in adult care rather than pediatric care predicted poor glycemic control after adjustment for study site, time between baseline and follow-up visits, sociodemographic variables, and disease factors (21).

Diabetes care visit attendance—Five studies examined frequency of diabetes care visits before and after transfer from pediatric to adult care, and all showed a decline in visit frequency (14, 15, 18, 19, 22). Of these five studies, two were associated with improvement in HbA1c (14, 15) and two were associated with no change in HbA1c (18, 19). In the German study of 101 patients, visits significantly decreased from 8.5 ± 2.3 visits per year pretransfer to 6.7 ± 3.2 visits per year posttransfer. Results were similar in the Swedish study of 104 patients, with mean visit rate significantly declining from 3.6 ± 1.1 visits per year in the pediatric clinic to 2.7 ± 1.1 visits per year in the adult clinics (15). In a small UK report of 33 patients, visits decreased significantly after leaving the pediatric clinic based on our statistical test of the provided data (14). The fourth study, based on clinic records of four health districts in the UK, showed that clinic attendance significantly decreased for a cohort of 96 patients (19). The rate of attendance dropped from 77% visiting the pediatric diabetes clinics every 3–4 months two years prior to transition to 24% maintaining this recommended standard 2 years after transition. The fifth report, based on clinic records in a single UK center, showed that patients missed significantly more appointments in the first year at an adult diabetes center than in the last year at the pediatric diabetes center (22). However, it is difficult to evaluate these changes in clinic attendance because the recommended number of visits in pediatric and adult care was not specified by the authors of these studies.

Rates of complications—Diabetes-related complications before and after transfer to adult care have been rarely evaluated. A study employing population-based, health administrative and survey data in Ontario, Canada evaluated frequency of screening for retinopathy in pediatric compared with adult care and found no change (23). A medical record-based study showed that retinopathy rates significantly increased from 4.8% at age 18 to 28.8% at age 24 in both males and females in Sweden, but these ages were not directly tied to pediatric vs. adult care (15). These two studies also compared diabetes-related hospitalization rates before and after transition and found no differences (15, 23).

Effects of transition interventions

There have been no published randomized controlled trials of transition interventions. Eight studies describe the outcomes of a transition intervention (13, 14, 24–29), but their methodologies vary in terms of inclusion of a comparison group and data both pre-and post-transition. These reports are reviewed in order of their methodology rather than being grouped by diabetes outcomes.

The methodologically strongest study evaluating the effect of a transition intervention on diabetes outcomes compared a structured transition program to a historical control group with pre- and post-data (24). The structured transition program included a transition coordinator, education about the transition process, and joint attendance of pediatric and adult diabetes care providers at the last pediatric clinic appointment and first adult clinic appointment. The historical control group was an unstructured transition process that was in place before the structured transition program and only included a scheduled appointment in the adult clinic and a letter summarizing the patient's medical history. HbA1c was significantly better at the first adult clinic visit and after 1 yr in the adult clinic for the structured transition group compared with the historical unstructured transition group, despite the fact that there were no group differences in HbA1c in the final year in pediatric clinic. However, the improvement in HbA1c with the structured transition program was not sustained after 3 yr. There was also a significant effect of the structured transition program on clinic attendance. The percentage of attended clinic appointments remained the same from the pediatric clinic to the adult clinic for the structured transition group compared with a decline for the unstructured transition group. However, the expected number of clinic appointments differed between the pediatric and adult clinics, with the pediatric clinic scheduling visits every 3 months and the adult clinic only every 6 months.

Another study that compared the outcome of a transition intervention program to a comparison group only had pediatric data available for the intervention patients and the controls used were also historical (25). Investigators assessed the use of a systems navigator model in the transition from pediatric to adult services, with the comparison data collected from a group of patients who were already in adult care. The intervention, called the Maestro Project, involved a website, bimonthly newsletter, monthly drop-in groups, and educational events. For the 64 patients involved in the intervention, attendance of at least one medical visit per year dropped only slightly from 95.3% the year before transition to 89.1% the year after transition. Attendance for the 101 patients in the comparison group, who had transitioned to adult care between 1 and 7 yr earlier, was much lower at 59.4% per year. When the comparison group was given the Maestro Project, attendance of at least one medical visit per year improved to 73.3%, which suggests effectiveness.

A further study had pre- and post-transfer data for the intervention group but no comparison condition (13). A structured transition intervention involved an informal discussion with 64 patients about the upcoming transition to adult care, introduction to the adult provider while in the pediatric clinic, and attendance of the pediatric provider at the first adult clinic appointment. As described earlier, HbA1c showed significant improvement after 1 yr in the adult clinic (see Table 1).

Two other studies compared the formats of adult clinics but did not have data available from pediatric care prior to the transition to adult care (14, 26). In a study conducted in the UK that reviewed the records of 33 patients who had transferred from pediatric diabetes care to either a Saturday young adult diabetes clinic or a conventional weekday adult diabetes clinic, there was no significant difference in clinic attendance after transition between the two formats (14). As the pediatric data were combined for all 33 patients, pre-and post-data for the two groups of patients could not be compared. The other report compared youth in Nebraska attending a young adult clinic (with nearly half referred by the pediatric diabetes clinic) to those who attended the conventional adult endocrinology clinic (with no referrals from the pediatric diabetes clinic) (26). There were no group differences in HbA1c, clinic attendance, or rates of diabetic ketoacidosis and microalbuminuria, but the sources of patients were different.

Finally, three studies aimed to evaluate the effect of a transition intervention but lacked a comparison group and data on participants prior to transition (27–29). All three studies reported benefits on glycemic control when using the first adult care visit as the baseline. In a Spanish study, HbA1c significantly decreased from the first adult appointment to 12 months later among 81 patients in a transition program that included scheduled visits and group sessions (27). In a study in the UK, a decrease in HbA1c from the first appointment to 8 months later was reported with the use of a two-stage transition process (i.e., the first year in a joint transition clinic and then transfer to an evening young adult clinic) (28). However, this study provided HbA1c data on 93 patients at the first appointment and 73 patients at the last appointment, without a comparison of the pre- and post-HbA1c for the subgroup of 73 patients who completed both appointments. The last study examined the use of a transition care program for 15 to 25-yr olds that included a transition coordinator arranging appointments and after-hours support (29). HbA1c decreased over the first four visits (which presumably occurred over the first year in adult care) for 191 patients of which only 91 transferred directly from pediatric care.

Conclusions

Despite the fact that clinicians and researchers have claimed that transition from pediatric to adult health care for youth with diabetes is accompanied by a myriad of problems, these appear to be anecdotal with very few methodologically strong studies available to examine the implications of the transfer of care on glycemic control and diabetes care visit attendance or to examine the effectiveness of transition interventions. To be fair, studies regarding the transfer to adult care for youth with diabetes rarely have been designed to address these questions. Some of the studies reviewed in this article were designed with the goals of assessing patients' perception of the transition process (18, 19), examining gender differences in diabetes care utilization in the transition process (15), and describing transition methods (13, 24, 25, 27–29).

The majority of studies reviewed here report that the transfer of care is associated with either an improvement or no change in glycemic control (12–19). However, serious methodological issues limit the conclusions that can be drawn from the results. The most important issue is that comparisons of glycemic control pre- and post-transfer can only be

made among patients who attend diabetes care visits often enough to have HbA1c measured. Thus, concluding that there was an improvement or lack of deterioration in glycemic control after transfer to adult care may be misleading as HbA1c data were not available for those patients included in the baseline who dropped out during follow-up in many of these studies (12, 13, 15–19). In fact, it is likely that HbA1c was higher among patients who were omitted. Two of the reviewed studies support this concept as they show that those with lower rates of adult visits had higher pediatric HbA1c values (16, 19). Also the mean age at transfer of care in these studies ranged from 17 to 21 yr. The effect of physical and psychosocial maturation on glycemic control over this age range confounds comparisons of those individuals transferring to adult care at a younger age compared with an older age.

Another issue to consider in assessing the studies that evaluate the effect of transfer on glycemic control is the nature of the adult care. The majority of studies that compared HbA1c pre- and post-transition (12–14, 17, 19) and reported a transition intervention (13, 24, 27, 28) had pediatric and adult clinics that were within the same health care system. While it is easier to follow patients who stay within the same health care system, acquiring data through this process may be biased as those patients who choose to stay in the same health care setting may have better diabetes care visit attendance and glycemic control compared with their peers who leave that health care setting.

Two recently published studies compared glycemic control in emerging adult patients still in pediatric care to those who had transferred to an array of adult care settings (20, 21). Both of these studies showed deterioration in glycemic control for those who had transitioned to adult care compared with those who had remained in pediatric care. This finding is in contrast to the studies showing an improvement or no change in glycemic control after transition to adult care within the same health system. While it is more difficult to track patients who leave the health care system, future evaluation of the effect of transfer of care on glycemic control should follow patients as they leave the pediatric health care system and go to an array of adult health care providers and assess differences from those who choose to remain either in pediatric care or within the same system.

The studies of health care visit frequencies clearly showed a decrease in attendance in adult care compared to pediatric care. However, these comparisons are a bit difficult to interpret as some studies measured number of visits per year (15, 18), while others measured the percentage of appointments made yearly (14, 19). Also, the targeted frequency of visits was less in adult care compared with pediatric care in some studies (14, 24). Regardless of the metric, the consistent finding of a decline in clinic attendance is extremely important for investigation of the effects of the transfer of care. Following demonstration of the impact of intensive diabetes therapy by the Diabetes Control and Complications Trial (30), most recommendations for children and adults with T1D are visits at least every 3 or 4 months.

The HbA1c level is often understood to be the gold standard for measuring diabetes outcomes because of its relation with diabetes complications (30). Given the concern of emerging adults dropping out of health care during the transfer to adult care, diabetes care visit attendance may be a more useful measure of diabetes outcomes for this age group than HbA1c. After all, it is better that an emerging adult in poor glycemic control sees a

physician who has the potential to intervene than an emerging adult in poor glycemic control drops out of health care.

Given the importance of diabetes care visit attendance for this age group, future research should examine predictors of clinic attendance. Because those with good pediatric clinic attendance have good adult clinic attendance (14), it may be useful to identify deterrents to regular clinic attendance among those in pediatric care. Undoubtedly, characteristics of the family and financial resources are related to pediatric clinic attendance. Research needs to be conducted to identify the barriers to care for both adolescents in pediatric care and emerging adults in adult care.

To prevent the problems associated with the transfer from pediatric to adult care, many groups of clinicians have already started to employ transition programs. A common component of many transition interventions is a linking of pediatric to adult clinic providers to facilitate the transfer of care. One study found that adult clinic attendance was higher for those who met the adult diabetes physician prior to transfer to the adult clinic (19). Another common component is early and frequent patient education about the transfer process. The Maestro Project, the only transition intervention employed with patients transitioning to a variety of adult providers, involved the use of a patient navigator to provide education support for patients and their families through a variety of media including website, book, and newsletter (25).

Although there are not sufficient data to endorse any one transition program, all of the programs reported higher rates of diabetes care visit attendance than seen in historical controls. One must interpret these findings with caution as the majority of studies failed to include a comparison condition, without which there is no information to indicate whether the benefit is due to unique features of the transition program, to increased attention from health care providers, or to changes in care over time. In addition, it is difficult to know which part (or parts) of the intervention are responsible for any benefit, as many of these programs are multifaceted. It is important to note that none of these programs have been evaluated in the context of a standard randomized controlled trial.

One of the motivations for this review was to alert clinicians and researchers to the dearth of quality data to guide the best format for transition from pediatric to adult care. The majority of studies to date are primarily observational studies which are limited by a lack of complete follow-up data on all participants after transfer and by a focus on the follow-up of those who remain in the same health care setting. Of the studies reporting the results of a transition program, there are also methodological shortcomings that need to be addressed in future studies. These shortcomings include a lack of an appropriate control group, the failure to randomly assign patients to a condition when a control group does exist, and the failure to collect data both before and after transition. Without a randomized controlled trial, it is difficult to conclude that any transition program has a benefit on glycemic control or diabetes care visit attendance. There are also conceptual shortcomings to the transition interventions to date. Because there is a lack of research on the differences in pediatric and adult approaches to diabetes care and whether any observed differences in pediatric and adult diabetes care contribute to differences in outcomes, it is difficult to design the most

effective intervention. Future research is needed to identify the differences in diabetes care provided by pediatric and adult clinics, so that effective interventions can be designed to prepare patients for these differences.

Despite the fact that there are few methodologically strong studies that explicitly address the impact of the transfer on diabetes outcomes, current standards of care by the American Diabetes Association have been put forth (10). These standards of care are primarily based on expert consensus or clinical experience in the management of youth with diabetes as they make the transfer from pediatric to adult health care. Although the guidelines have been developed by leaders in the field who have a broad range of experience with youth with diabetes, it is important for future research to establish the best practices that will facilitate this transition. Our hope is that this review spurs methodologically strong research in the area of transition, and our aspiration is the empirical validation of these clinical recommendations.

In conclusion, the literature to date demonstrates a decline in diabetes care visit attendance following the transfer to adult health care. While studies reporting glycemic control immediately pre- and post-transfer do not demonstrate deterioration, two recent longitudinal studies indicate deterioration in glycemic control for emerging adults who transferred to adult care compared with their peers who remained in pediatric care (20, 21). As diabetes outcomes in emerging adults may be associated with the processes and timing of transition, it is important for future studies to identify the processes that offer the greatest benefits to overall psychological and physical well-being for those making the transfer from pediatric to adult care.

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Table 1

Effect of transition to adult care on HbA1c: results of observational studies

Authors	Study design	Original sample size (% male)	Location	Time frame	Mean age in years ± SD at the transfer from pediatric to adult diabetes care (range, if specified)	Change in HbA1c pre- to post-transition	Mean pre HbA1c % ± SD (mmol/mol)	Mean post-HbA1c % ± SD (mmol/mol)	HbA1c methodology
Busse et al. (18)	Single preclinic and multi postclinics	101 (46%)	Germany	1996–2003	17.8 ± 0.9	No difference	8.5 ± 1.5 (69 ± 13)	8.3 ± 1.6 (67 ± 18) n = 44	Not specified
Johnston et al. (14)	Single preclinic and multi postclinics	33 (42%)	UK	2000–2001	17	Improve (X2 = 17.6, p <0.001)*	n = 44		Not specified
Kipps et al. (19)	Multi pre- and postclinics	229 (57%)	UK	1999	17.9	No statistical analysis†	10.1 (87)‡ n = 229	9.9 (85)‡ n = 141	High performance liquid chromatography (HPLC)
Neu et al. (16)	Single preclinic and multi postclinics	99 (47%)	Germany	1998–2008	21.8 ± 2.8	No statistical analysis	7.7 ± 1.2 (61 ± 13) n = 99	At 1 year: 7.3 ± 0.9 (56 ± 10) n = 34 At 5 years: 7.1 ± 1.6 (54 ± 18) n = 12	Not specified
Orr et al. (17)	Single pre- and post-clinic	82 (61%)	USA	Not provided	17.3 ± 0.8 (13.8–19.6)	No difference	9.9 ± 1.8 (85 ± 20) n = 77	10.2 ± 1.9 (88 ± 21) n = 77	Microcolumn (reference value <8.0%)
Salmi et al. (12)	Single pre- and post-clinic	61 (57%)	Finland	1980–1983	17.5 ± 0.5 (16.5–18.8)	Improve	11.2 ± 2.2 (99 ± 22) n = 49	9.9 ± 1.7 (85 ± 19) n = 49	Ion exchange microcolumn (reference value 4.5–8.0%)
Sparud-Lundin et al. (15)	Single preclinic and multi postclinics	104 (51%)	Sweden	1996–2006	19.8 ± 1.3	Females: Improve	Females age 18: 9.4 (79)	Females age 24: 8.5 (69)	Not specified
						Males: No difference	Males age 18: 9.0 (75) n = 103	Males age 24: 8.5 (69) n = 80	
Vanelli et al. (13)	Single pre- and post-clinic	73 (59%)	Italy	1994–2002	21.0 ± 0.95 (20–23)	Improve	8.8 ± 2.1 (73 ± 23) n = 64	7.6 ± 1.1 (60 ± 12) n = 64	Pre: DCA 2000 Post: HPLC

HbA1c, hemoglobin A1c.

*Created categorical variable.

†No statistical analysis, classified as no improvement.

‡Calculated mean based on published data.