

## RESEARCH ARTICLE

# Transition in Type 1 diabetes mellitus from a tertiary pediatric center: what are we doing before they walk out the door?



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### Summary Points

- There is no gold standard model of care on which to base the service provision of transitional care in Type 1 diabetes.
- A planned approach to the transition of these youth is essential.
- Youth should be encouraged to continue medical review in a specialist setting.
- The provision of a comprehensive medical summary should be standard for all transitioning youth, and is a practical aspect of care that can readily be improved upon.
- Accurate contact details for both the youth and their general practitioner are necessary so that our adult colleagues can ensure optimal clinic follow-up post-transition.

**SUMMARY** **Aims:** Planned transition to adult services in the form of a formal written document should be standard practice in the management of young adults with chronic disease. The aim of this audit was to provide details on the process of transition in youth with Type 1 diabetes mellitus at the Royal Children's Hospital, Melbourne, Australia. **Methods:** This was a retrospective review of patients with Type 1 diabetes mellitus who transitioned from the Royal Children's Hospital between June 2009 and June 2011. **Results:** A total of 180 youth were transitioned from pediatric services at the Royal Children's Hospital to adult hospital services during this time. The mean ( $\pm$  standard deviation) age of transfer was  $18.4 \pm 0.7$  years, and the majority of youth were transitioned to centers within the Melbourne metropolitan area. Pertinent clinical details were often missing from transition referral letters, which were sent in only 82.8% (149/180) of cases. Transition occurred in an apparently unplanned way or without physician input for 30.6% (55/180) of youth in this cohort. **Discussion:** A high standard of referral documentation should be routine for all transitioning youth, to serve as an introduction to our adult colleagues and to provide a comprehensive medical summary. Emphasis should be placed on the inclusion of accurate contact details to allow for optimal follow-up.

Transition of medical care is defined as “a purposeful planned process that addresses the medical, psychosocial and educational needs of adolescents and young adults with chronic physical and medical conditions as they move

from child-centered to adult-oriented health-care systems”. Specific interventions can aid engagement with services, but the effects may be sustained only for the duration of the intervention [1,2] and often there is a high drop-out rate

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notwithstanding the implementation of specialist support [3,4]. Despite widespread commentary on the transition of youth with Type 1 diabetes mellitus (T1DM) [5–7] and encouraging reports [8–10], a universally suitable approach to the transition of these young adults has not yet been defined. Disengagement from hospital services is associated with poor clinical outcomes (as determined by glycated hemoglobin [HbA<sub>1c</sub>] values), an increased disease burden and neglect of diabetes management [11,12], and as such, efforts should be made to retain youth with T1DM within the hospital system.

A survey of transition at the Royal Children's Hospital (RCH) in Melbourne, Australia performed 10 years ago highlighted the fact that only 49% of young adults with chronic medical conditions were either transferred or had a transfer plan to an adult hospital [13]. Since then, well-defined generic principles of transition and consensus guidelines for T1DM transition have been published, highlighting the importance of written transfer plans [14–16]. The RCH diabetes clinic provides a typical protocol-driven model of care with review at hospital clinics every 3 months, consistent with national and international guidelines. Historically, transition of diabetes care has occurred after completion of secondary schooling (high school). Various models to enhance transition outcomes have been trialed at RCH, including transition symposia, online educational material, adult physicians working within the RCH clinic and RCH staff attending young adult diabetes clinics within some of the receiving adult hospitals. Despite this, follow-up data suggests that up to 30% of young adults with T1DM are lost to follow-up within 2 years of transition from our pediatric clinic, which is not dissimilar to other reported series [17–20]. Current transition practice at the time of writing involves a discussion between the treating physician and the youth regarding the most appropriate adult referral center, followed by the dictation of a transition referral letter at the time of the final RCH clinic visit. In order to understand the antecedents to suboptimal transition outcomes we aimed to describe the patient and treatment characteristics at the time of transition and to evaluate the quality of transition documentation, which has not previously been assessed from a diabetes perspective. The aim of this audit was to provide details on the process of transition in youth with T1DM at RCH.

## Methods

This was a retrospective descriptive audit. Data were retrieved from a combination of our established T1DM database, the hospital's off-site dictation facility (Ozscribe PTY Ltd 2011, Victoria, Australia) and the hospital's electronic scanned medical record facility. Charts were reviewed to document:

- Mean age of transition to adult services
- Mean duration of diabetes prior to transition
- Glycemic control at the time of transition
- Insulin regimen at the time of transition
- Adult service/institution of referral
- Mode of referral (i.e., was a transition letter dictated or not?)
- Mean frequency of clinic attendance in the 12 months prior to transition
- Level of clinical detail provided by transition letters

The date of the last RCH diabetes clinic was taken as the point of transition. The adult diabetes service to which each youth was referred was identified from the transition letter where available. Youth were subdivided into groups according to transition letter status. 'Planned' transition was defined as dictation of a transition letter up to 30 days after the final RCH visit. 'Unplanned' transition occurred after this time and a designation of 'unilateral cessation of care' was made where no transition letter was available. Clinicians identified 12 key pieces of information (date of diagnosis, mode of presentation, antibody status at diagnosis, current insulin regimen, previous insulin regimens, current HbA<sub>1c</sub>, previous HbA<sub>1c</sub>, comorbidities/general medical history, complication status, general practitioner details, copy of the letter to the youth or their family and mobile contact number for the youth) that should reasonably be included in a transition letter. The quality of the referral letter content was then determined using a scoring system (maximum of 12 marks), with one mark given for reference to each of the above. 'Complication status' refers to the diabetes-specific assessment that includes retinal examination, blood pressure measurement, serum cholesterol, urea and electrolytes, and urinary microalbuminuria. HbA<sub>1c</sub> was measured using HPLC ion exchange (Bio-Rad, D10; Bio-Rad Laboratories Inc., CA, USA). Student's t-test

(continuous variables) or  $\chi^2$  analysis (comparison of proportions) were used to compare the 'unplanned' and 'unilateral cessation of care' groups to the theoretically ideal 'planned', where a p-value of  $<0.05$  was considered significant. Institutional approval was granted by the RCH human research ethics committee in July 2011 (HREC 31147A).

## Results

Data extraction was carried out on July 2011. A search of the RCH diabetes database identified all active and inactive youth aged 15–22 years ( $n = 897$ ). From these, 180 youth (male = 99) with T1DM were identified as having had their most recent RCH diabetes clinic visit July 2009–June 2011, defining the timing of 'transition'. Age (mean  $\pm$  standard deviation) at transition was  $18.4 \pm 0.7$  (15.6–20.2) years, with duration of diabetes of  $8.6 \pm 4.4$  (0.4–18.1) years and median HbA<sub>1c</sub> of  $8.2\%$  (range: 5.5–15.5%). HbA<sub>1c</sub>  $\leq 7.5\%$  was attained in 56 out of 180 youth (31.1%). Insulin regimens consisted of continuous subcutaneous insulin infusion in 56 out of 180 (31.15%), multiple daily injections in 92 out of 180 (51.1%), twice-daily free-mixed insulin in 23 out of 180 (12.8%) and twice-daily premixed insulin in 9 out of 180 (5%). The adult referral center was detailed in either the diabetes database or within the content of the transition referral letter for 165 out of 180 (91.7%) youth. The majority of youth were referred to tertiary centers ( $n = 151$ , 91.5%), with the remainder referred to either private endocrinologists ( $n = 6$ , 3.6%) or regional centers ( $n = 8$ , 4.8%). In the 12 months prior to transition, youth had a mean clinic attendance frequency of  $3.2 \pm 0.9$  appointments (range: 1–5), with no correlation between clinic attendance frequency and the pretransition HbA<sub>1c</sub> (correlation coefficient = -0.02).

Transition letters were available for 149 out of 180 (82.8%) youth who attended clinics involving ten clinicians (six consultants, four fellows). 'Planned' transition was initiated for 125 out of 180 (69.4%) youth, with transition letters dictated prior to, on the day of, or within 1–30 days of the last clinic visit for 12, 91 and 22 youth, respectively. 'Unplanned' transition occurred for 24 youth (13.3%), with letters dictated more than 30 days after the transition point. **Table 1**, provides a summary of the patient characteristics of the subgroups. 'Unilateral cessation of care' ( $n = 31$ ) occurred when transition was either: not mentioned in any record of

hospital contact ( $n = 11$ ); apparently planned by the treating physician (as per the case notes) but without an ensuing letter ( $n = 12$ ); reported to have occurred by external sources ( $n = 3$ ); or occurred with allied health telephone contact without physician input ( $n = 5$ ). The interval (mean  $\pm$  standard deviation) since the last RCH review of this group at the time of data extraction was  $1.2 \pm 0.4$  years (range: 0.6–2.0). The overall mean score of the quality of these letters was 7.9 out of a maximum of 12 marks with no difference seen between 'planned' and 'unplanned' transition letters (8.0 vs 7.7,  $p = 0.6$ ). In descending order of frequency, the percentage of transition letters that referred to each of the stated clinical details was: current insulin regimen in 97.6%; complication status in 90.4%; current HbA<sub>1c</sub> in 89.6%; previous HbA<sub>1c</sub> in 84%; mode of presentation in 71.2%; date of diagnosis in 66.4%; general practitioner details in 60.8%; previous insulin regimens in 56.8%; antibody status in 48%; the presence/absence of comorbidities or general medical issues in 47.2%; a copy to the family/youth in 42.4%; and mobile contact number for the youth in 8.8%.

## Discussion

This report describes the transitioning group from the RCH diabetes clinic to adult diabetes care services over a 2-year period. The young adults described are a typical Australian adolescent T1DM cohort in terms of their age and HbA<sub>1c</sub> at the time of transition in a universal healthcare system. Given the representative nature of the group and formulaic model of care within the RCH diabetes clinic, there appears to be no idiosyncratic characteristic of either the clinicians or the overall patient group that would mitigate against successful transition planning.

The observation that diabetes care at RCH was terminated in an apparently abrupt or unplanned manner in approximately one-third of patients is a particular cause for concern. Within this cohort, 31 patients (or 17%) had no transition letter and thus appear to have unilaterally withdrawn from tertiary hospital diabetes care prior to formal transition. These youth are younger, and their median HbA<sub>1c</sub> is higher than that of the other groups. Given that they appear to have disengaged from pediatric hospital clinics, this may be an underestimation of their true glycemic control.

**Table 1. Characteristics of various patient groups when last seen at Royal Children's Hospital, Melbourne, Australia.**

Patient characteristics	Patients who had letters dictated <30 days of last clinic visits 'Planned' transition n = 125	Patients who had letters dictated >30 days of last clinic visit 'Unplanned' transition n = 24	Patients who had no transition letter at all 'Unilateral cessation of care' n = 31
Age at transition (mean years ± SD)	18.5 ± 0.6	18.0 ± 0.6*	18.0 ± 1.0**
Duration of diabetes (mean years ± SD)	8.6 ± 4.2	8.0 ± 4.9	9.3 ± 4.9
Median HbA <sub>1c</sub> (%)	8.2	9.0	8.4*
Number of clinic visits per year in 12 months prior to 'transition' (mean ± SD)	3.3 ± 0.9	3.2 ± 0.9	2.8 ± 0.8*
Percentage on two injections per day (number)	14.4% (18)	20.8% (5)**	29% (9)**
Percentage on MDI (number)	52.8% (66)	41.6% (10)**	66.7% (16)**
Percentage on CSII (number)	32.8% (41)	37.5% (9)**	19.3% (6)**

The p-values are 'planned' compared with 'unplanned' and 'cessation of care'. No significant differences were seen between 'unplanned' and 'cessation of care' groups.  
\*p < 0.05; \*\*p ≤ 0.01.  
CSII: Continuous subcutaneous insulin infusion; HbA<sub>1c</sub>: Glycated hemoglobin; MDI: Multiple daily injections; SD: Standard deviation.

Our rates of written transfer letters (82.8%) are an improvement on those previously reported at RCH [13], but the quality of letters is variable. Whilst the majority of written letters contain approximately eight out of 12 key pieces of information, many omitted significant relevant clinical information. The fact that approximately one-third of letters did not include a date of diagnosis or the family doctor contact details, and half of letters did not mention presence or absence of comorbidities, is disappointing. There appears to be no difference in quality between 'planned' and 'unplanned' transition letters so the context in which the letter was written appears not to be a contributing factor. The issue of the quality of transition letters can potentially be improved, but the rate of disengagement of youth from the clinic setting prior to formal discharge from pediatric services may not be so easily remedied.

While the findings of this in-house audit may not be directly relevant to the wider endocrinology community, it serves to highlight several important issues. 'Transfer' is the event of moving from pediatric to adult services, whereas 'transition' refers to the process that precedes and follows this time point. From previous data, 30% of RCH patients are 'lost' after transition to adult services [17], but the follow-up information pertaining to this particular cohort is not available. There is no gold standard model of transitional care on which to base clinical practice. Expert consensus advises that it should be a planned and dynamic process [16,21], giving the opportunity to prepare and involve youth in the necessary decisions [22]. In the absence of

follow-up data or a formal transition program, this study uses the transfer point to determine the timing of transition. This is an inherently flawed premise as it does not allow for a prolonged disengagement from services in the 'unilateral cessation of care' group. However, a mean time interval of 1.2 years since last review supports the hypothesis that these youth had in fact disengaged from our service and that their most recent clinic visit was in fact the final one. The fact that the allied health team had been informed about engagement with adult services without playing an active role in the planning of this process for some of this group reflects the intention of these youth to disengage from pediatric care.

Deficiencies in the process of transition from pediatric services have long been recognized by clinicians on both sides of the transition pathway. A more planned process may improve clinic 'drop-out' rates and the use of proforma-style letters may enhance the quality and consistency of transition letters that is provided to our adult colleagues and has recently been introduced into our clinics. A formal written transition referral document, detailing all relevant medical details, is a prerequisite in order to summarize pediatric medical care and to serve as a focus point for the first adult clinic consultation. It is particularly important to ensure documentation of accurate contact details for both youth and their treating general physician. This will allow adult clinicians to optimize their ability to inform youth of scheduled appointments, and is of crucial importance for the follow-up of nonattendances. Assessment of the impact of

improvements in documentation would require prospective studies in order to demonstrate whether or not this measure has a positive effect on losses to follow-up.

The intention of the authors was to focus on a practical aspect of the transition process that should be a fundamental part of routine clinical care. In contrast to many other aspects of transitional care it is also readily amenable to change, regardless of the availability of resources or healthcare system. In this era of increasing healthcare information technology and electronic records, access to medical information of patients with chronic diseases should be more readily available in order to facilitate the provision of accurate and comprehensive transition documents [23,24]. Constant review of patients approaching the age of transition, with early discussion of follow-up options, should be standard practice for all clinicians. Transition issues need

to be addressed before our patients ‘walk out the door’ of pediatric care.

#### Author contributions

*M White researched data and drafted the manuscript. MA O’Connell contributed to the discussion, wrote the manuscript and reviewed/edited the manuscript. FJ Cameron contributed to the discussion and reviewed/edited the manuscript.*

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*The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.*

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