

Care of adolescents and young adults with diabetes – much more than transitional care: a personal view

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ABSTRACT

There is increasing recognition that type 1 diabetes mellitus (T1DM) acquired in childhood and adolescence requires a sophisticated approach that facilitates better self-management through adherence to generic principles in managing chronic disease in this age group, allied to the complex clinical needs of managing T1DM and related conditions. Transitional care should be seen as a process over time supported by both paediatric and adult diabetologists within a multidisciplinary team, given the complementary skills that can be brought to bear. Undoubtedly, there is a need for more effective training of all healthcare professionals working in this service. However, the accumulation of older teenagers over time and new diagnoses in those aged 19 years or more confirms that a new paradigm is necessary for the successful care of young adults beyond transitional care. Traditional clinical models will often not work for those in employment and higher education, with evidence that ongoing engagement following transfer to adult services often ceases. The alarming evidence of progressive complications in T1DM of longer duration in patients under the age of 40 years is a wake-up call to transform the care of this most vulnerable group.

KEYWORDS: Type 1 diabetes, transitional care, children and young people, insulin pump, National Paediatric Diabetes Audit, National Diabetes Audit, diabetic ketoacidosis, glycated haemoglobin, diabetes complications

Introduction

Although there is increasing recognition that monogenic cases of diabetes (MODY) and type 2 diabetes mellitus (T2DM) linked to obesity in patients under the age of 25 years can account for over 2% of those with diabetes, most younger patients with diabetes will have type 1 diabetes mellitus (T1DM). Managing this condition through the hormonal and psychosocial turbulence of puberty and adolescence poses unique challenges.

The ideal model for effective support of children and young people (CYP) is delivered by a fully resourced multidisciplinary

team with specialist medical and nursing clinicians from both paediatric and adult diabetes services, with dietician and psychology support. The concept of ‘transitional care’ as a process over several years has been adopted in the UK and has been incorporated within a Year of Care Best Practice Tariff in England for children and young people with diabetes up to the age of 19 years.

However, many challenges remain in delivering this for CYP with T1DM in the UK. Surveys have established continued gaps in the provision of transitional diabetes care.¹ This is most evident when one examines the glycaemic outcome measures in children and young people in the UK compared with other European countries. In the last National Paediatric Diabetes Audit (NPDA) (2010–2011), over 30% of patients had levels of haemoglobin A_{1c} (HbA_{1c}) >80 mmol/mol (9.5%),² whereas in Germany and Austria over the same time period, only 10% exceeded an HbA_{1c} of 75 mmol/mol (9%).³ Within the UK, there is evidence from the NPDA and the Atlas of Variation of Healthcare for Children and Young People of marked differences in care processes and outcome measures that are likely to be amenable to improvement.^{2,4}

There are many examples of good practice in transitional care that have been promoted in publications from National Health Service (NHS) Diabetes.^{5,6} These are often the consequence of many years of hard work developing such services and/or accompanied by adequate resourcing of the services. Previous online self-assessment tools are limited in their ability to evaluate the quality of services because they are subjective, although they can provide a useful baseline from which to develop services. However, the current peer reviews of all CYP diabetes services in England will offer a more objective assessment and the opportunity to minimise variations in practice.

The most recent reports from the 25-year follow up of the Diabetes Control and Complications Trial (DCCT) of intensive control deliver vital messages of a long-lasting legacy effect that is particularly pertinent for CYP with T1DM.⁷ The trial conclusively demonstrated tight glycaemic control, with a maintained mean HbA_{1c} of 53 mmol/mol (7%) compared with 75 mmol/mol (9%) in the conventionally treated group; such control led to significant reductions in the evolution and progression of microvascular complications over the 9 years following the initiation of the trial.

The Epidemiology of Diabetes Interventions and Complications (EDIC) study⁸ follow up over the subsequent 9

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years was while the two groups were no longer differentiated by glycaemic control (mean approximately 65 mmol/mol [8.1%]). However, over that period, there was further separation of the two groups in terms of progressive vascular damage. At 17–25 years, these differences persisted and, in some cases, were even more apparent, especially for cardiovascular outcomes.^{9,10} There were 195 adolescents of the age of 13–17 years initiated in DCCT (14% of total study group) whose benefit was at least as great as the overall cohort.⁸ The message could not be clearer – if tight glycaemic control (HbA_{1c} 50–60 mmol/mol) can be achieved for the first decade of T1DM in younger patients, a legacy of reduced complications could follow for a generation, assuming maintained levels of glycaemia of 65 mmol/l or less without major hypoglycaemia after the initial 10 years of therapy.

In this article, I outline current strategies and recommendations for the most effective transitional care to help achieve these desirable outcomes, identify the challenges to delivery of this and the additional issue of care post-transfer, and comment on the need to consider those young adults with T1DM who present or need care during their later teenage and early adult years.

What is transitional care in diabetes and how to do it well?

The generic approach to the transitional care of adolescents with chronic disease is important and has been put in perspective by several authorities.^{11,12} Transition in healthcare should be considered as only one part of the evolution from dependent child to independent adult and should be seen as a process rather than as a finite event, essentially a ‘period of time during which there is planned, purposeful and supported change in a young adult’s diabetes management from child orientated to adult orientated services, mirroring increasing independence and responsibility in other aspects of their life’.¹² Some aspects can rightly be considered applicable for several conditions. The ‘Ready Steady Go’ concept has been successful for diabetes, chronic kidney disease and other long-term conditions.¹³

An expert working party has produced recommendations and core measures for successful transitional diabetes care (Boxes 1 and 2).⁶

The guidance defined 10 key aspects (‘the 10 Ps’) that needed to be addressed:

- > the person with diabetes
- > the parent (carer)
- > partnership with the health care team
- > participation of the individual in self management
- > professional training
- > planning of transition and transfer and the process of transition
- > a place identified for clinic care that is appropriate
- > effective input to pumps
- > pregnancy and pre-existing conditions.

Where effective, the service would ensure adequate knowledge of diabetes, self-advocacy skills, approaches to health and lifestyle, activities of daily living, vocational and psychosocial aspects. These would need to align with a realistic parental-carer’s perspective.

Box 1. Recommendations for transitional diabetes services.

- > All diabetes units sign up to the core values of a quality consultation
- > Agree minimum standards for the contents of a transition policy, based on national guidance and evidence
- > Ask departments to ensure that their policy is in line with the minimum standards, initially through the Paediatric Diabetes Network coordinators and then formally through self-assessment, peer review and the Best Practice Tariff (BPT)
- > Ensure that there are paediatric and adult lead diabetologists working in collaboration in each unit and that there is an adult diabetologist in each of the regional paediatric networks
- > Each unit to identify training needs for paediatric and adult teams around young adult communication and consultation skills
- > Develop a health plan prompt sheet; this would include prompt sheets for both the professional and young adult on all aspects of health
- > Develop a transition planning process prompt sheet for professionals to improve their transition process
- > Improve the standard relating to transition in the BPT with requirements possibly taking into account the age group 18–30 years

Paediatric and adult diabetologist teams working together

Effective transitional care, by definition, requires input from both paediatric and adult diabetologists committed to working together. Their approaches could be likened to looking at the same situation from different ends of a telescope because the perspectives can differ. This in itself is why a well-functioning transitional service can fully meet the needs of CYP. The paediatric department will have expertise understanding growth and development, child protection and psychosocial issues, family therapy and dynamics. In addition, paediatricians might better understand the impact of the challenges that puberty places on diabetes self-management, such as dealing with drugs, alcohol and sexual experience. Understanding of the altered perceptions of body image and substance abuse might increasingly span both services. Adult diabetes services might better detail issues of contraception, pregnancy, sexually transmitted diseases, driving and awareness of hypoglycaemia, and therapies for insulin resistance and the complications of diabetes. The team together can facilitate the process of change from parental responsibility to the state of understanding the need for self-management.

The increasing co-occurrence of obesity in T1DM in CYP might raise issues of how and when to consider insulin-sensitising therapies. Nutrition and exercise are complex areas and dieticians with an understanding of the physiology of exercise and its impact on glycaemia can support many young people with diabetes and an active lifestyle.

There has always been more ready access (albeit inadequate from recent surveys)^{1,14} to psychological assessment in paediatric compared with adult diabetes services. This might

Box 2. Core process measures of effective transitional diabetes care.

- > An identified lead for transition in each paediatric and adult diabetes service
- > A joint paediatric–adult transition policy
- > Evidence of consultation and user involvement in the policy development
- > The transition period should last at least 12 months, with input from paediatric and adult teams over that period with at least one combined appointment
- > Experience of care audit
- > Evidence of use of a shared care-planning template
- > DNA rates monitored and followed up over the course of the transition period
- > Reduction in admissions for emergency diabetic ketoacidosis and/or hypoglycaemia
- > % HbA_{1c} levels <58 mmol/mol
- > Outcomes from a care audit to be undertaken by units

better enable a more motivational approach to consultations as well as enabling treatment of important psychological distress. Successful delivery of best self-management would build on behavioural change delivered through education from the multidisciplinary team (MDT) alongside a medical model of care, which should be considered achievable. It has been suggested that chronic disease in the years of adolescence should be managed in a generic fashion that recognises common challenges.¹⁰

However, it is evident that self injection of insulin with blood glucose monitoring four or five times per day, the potential of disabling hypoglycaemia, and the dietary issues and challenge to fit this into a teenage lifestyle pose unique challenges in comparison with a young person living with asthma or chronic renal or neurological disease. The ideal approach would be multidimensional, with disease-specific and generic components.

Despite the improvements recorded in the last survey of over 75% of services in the UK reporting a process for transfer from paediatric to adult services,¹ one has the distinct impression that, for a few services, transitional care does not exist. Variation in age at transfer was notable in that survey. The recent NPDA raises the possibility that separation anxiety is not only a concern for parents, but could also be an issue with paediatric diabetologists, in that almost 400 cases (1.7% of the total) studied were adults aged 20–24 years.² This reinforces the notion that the transfer of care requires further refinement.

The role of regional diabetes children and young people networks

Regional diabetes CYP networks were established through NHS Diabetes and enabled the first efforts to look to delivery of best practice through agreed common protocols and, where possible, enabling cover for out-of-hours care and support. The abolition of NHS Diabetes in England will hopefully not undo the momentum through a linked continuation with the Best

Practice Tariff (BPT) that will maintain the running costs of regional networks, although it has recently been argued that the operation of the BPT in England will create two-tier care of CYP across the four nations of the UK.¹⁵

Remaining challenges

The provision of services for CYP should consider the demographics of the caseload. The necessary focus on transitional care does not take account of the epidemiology of new-onset T1DM in the age group beyond the usual 19-year-old cut off for transfer to adult diabetes services. Although the annual incidence of new diagnoses of T1DM remains greatest in children aged 9 years or less (47.2 per 100,000) compared with those up to the age of 19 years (29.4 per 100,000), or those aged 20–29 years (19.7 per 100,000), the prevalence of diabetes in the 19–30 age group is greater than among those who are 19 years old or less.^{16,17} The National Diabetes Audit demonstrated that, of the total registrations with T1DM in England, 3.5% were 10 years old, 4.5% were 11–15 years old, 6.5% were 16–20 years old, but 6.6% were 21–25 years old and 7% were 25–30 years old.¹⁷ The NPDA age distribution was approximately one-third 12 years old or less, one-third 12–15 years old, and one-third in the transitional 16–19 year age group.² This distribution should make it clear that the future and current care of these young people requires early engagement with adult services to best ensure effective continuity of care.

Diabetes through puberty poses particular strains on the risk of worsening control, with insulin resistance and accelerated development of early complications, but it could be argued that the need for comprehensive care of a 20-year-old with T1DM for 1 year after diagnosis is as necessary as for a 20-year-old who has lived with the condition since the age of 10. The current BPT provides an opportunity for excellent care that will be impossible in most services to continue to the same level beyond the age of 19 years.

There is a real perversity in offering a service with medical, nursing, nutritional and psychology support with eight contacts a year and 3-monthly visits till the age of 19 years, which then terminates abruptly to be replaced ideally by a young adult clinic or, in many cases, absorption into a more generic adult DM service with considerably less resource.

The lack of BPT extending at least till the age of 25 years and beyond is regrettable. In many ways, the issues from the age of 19 onwards might be considered to extend beyond the age of 25. The marketeers who developed ‘Club 18–30’ must have recognised a common thread in this age group. Higher education and employment issues are just two factors that impact on diabetes care that can reasonably apply till the age of 30.

The care of T1DM overall remains a concern, with the NDA revealing worrying evidence of poor outcomes.¹⁷ In England, given that 90% of the diabetes population have T2DM, the Department of Health perspective is understandably that diabetes should be predominantly managed in primary care. The recent ‘Lost Tribe’ campaign from the Association of British Clinical Diabetologists (ABCD) highlighted the need to ensure an effective commissioned service for all patients with T1DM where there was ready access and supervision by a consultant-led MDT service.¹⁸ Inevitably, this does not always happen.

The process of transfer from transitional diabetes clinics has been identified as a further challenge¹⁹ and has been recognised in Hertfordshire, where audits of transfer demonstrated that, despite effective transitional care, attendance at the young adult service on one to two occasions was frequently followed by failure to reattend.

As a consequence, practice-based risk registers of young adults with T1DM who have become disengaged and fail to attend specialist clinical services have been developed. The reasons for the lack of continuity of care are speculative, perhaps partly through issues of moves to higher education elsewhere and through employment issues, but inevitably might reflect disillusionment with a less-focused service for CYP.

The key issues of managing young people with T1DM at university is currently the subject of active research – whether to deliver care at the university location or in holiday time back at the family base might matter less than the potential for some cases ‘falling between two stools’ and never returning to care.

The opportunity through better-integrated care between specialist services and generalist primary care could address this, although more imaginative non-traditional clinic-based models will be required to support young adults of working age in employment or in higher education. The effective management of these challenges could in turn enable a paradigm shift in care planning for the bulk of older working adults with T1DM.

Education of healthcare professionals providing care for CYP with diabetes in adult services in particular remains patchy and the Royal College of Physicians (RCP) is actively engaged with the specialist societies in efforts to ensure generic training in adolescent medicine of doctors and nurses working in acute hospitals, linked to specific training within the curricula of diabetes and endocrinology.

Special considerations

Continuous subcutaneous insulin infusion (CSII) pump services are currently the subject of national audits that have reported on coverage.²⁰ Access to pumps for CYP was temporarily restricted following a decision by NHS England that all new cases could only initiate treatment in a tertiary centre where funding would be based, although this issue now appears to have been resolved. Before this, CSII pumps were started according to adherence to National Institute for Health and Care Excellence (NICE) criteria in specialist secondary care centres.

Although CSII use remains well below the 5% of patients with T1DM in UK who are suitable and likely to benefit, there might have been greater readiness to introduce the technology in CYP services than in some adult diabetes services. This creates the challenge of demonstrating lasting clinical benefit, with some audits reflecting differential attainment of glycaemic control compared with adults using insulin pumps.^{21,22} It would not be possible to determine whether this reflected failure to fully exploit the technology in some younger cases, poor patient selection or whether the observation of worse control and more frequent withdrawal of insulin pumps is a marker of the challenges of using pumps through puberty. In any event, many adult services currently operate separate insulin pump and young adult clinics.

Therefore, there might be a need to better develop transitional care specifically for patients using insulin pumps at least until wider use of insulin pumps leads to greater expertise among adult diabetes teams, with less need for a separate service and the potential for a more seamless transition of this group of patients. The wider use of new technologies, such as continuous glucose monitoring systems (CGMS), to identify asymptomatic hypoglycaemia and/or marked glycaemic instability will support more cases in all specialist T1DM settings.

Screening in CYP services for comorbid related conditions, especially thyroid and coeliac disease (in addition to the less well-recognised risk of Addison’s disease in T1DM with thyroid disease), was recommended by the NICE Quality Standards. This important aspect of process in many CYP services should be rolled out to the T1DM services for those who are 19–30 years old, particularly those who developed diabetes after the age of transition. These nuances of care might be best identified with ‘the two heads are better than one’ principle in transitional care.

The recognition of early-onset retinopathy and microalbuminuria is a good example where adult diabetologists working with paediatricians might not only better recognise the potential transient reversible nature of some cases, but also identify those at highest potential future risk where, in a limited number of cases, modulation of the renin–angiotensin–aldosterone system (RAAS) and statins might be considered.

One contemporary unresolved challenge that requires effective coordination is the inpatient care of those who are 16–19 years old with emergency admissions related to glycaemic instability (diabetic ketoacidosis [DKA], non-ketotic hyperglycaemia or hypoglycaemia). The NPDA recorded that 35% of DKA admissions in males and almost 60% of females were in this age group, and the NHS Atlas confirmed wide regional variation in the admission rates.^{2,4}

At present, almost every acute hospital will admit these vulnerable young patients to adult medical wards and often not under specialist teams. The care of DKA in those aged 19 years or less requires subtle changes to standard protocols for adult care and raises the need for 24-h access to specialist care, which in many units will not be feasible. The promotion of 7-day working for diabetes specialists in adult teams might help resolve this issue.

Conclusions

Optimal support of CYP with T1DM encapsulates the ethos of seamless care. This requires a commitment to better training of all healthcare professionals who have clinical contact in hospital and community settings, and continued close cooperation between paediatric and adult diabetes teams. Such services have clearly outlined standards, which can be the basis for regular MDT peer review and appraisal.

Integrated care led by specialists in and out of hospitals with innovative non-traditional models of care offers the best opportunity to deliver the improved glycaemic control and outcomes demonstrated in North America in the DCCT^{8–10} and from routine care in the Teutonic states.³ The relatively small cohort of CYP with diabetes in the UK could achieve this if there is the opportunity to access holistic care, as has been outlined.

However, the abrupt change in approach after transfer to adult services is not only illogical, but also might contribute to the poor outcomes one decade on. A fundamental change in the model of care for young adults with diabetes will be necessary to reverse the avoidable morbidity and tragic premature mortality. ■

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