

Challenges of emerging adulthood-transition from paediatric to adult diabetes

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to improve the experience for child, parents and also the multi-disciplinary team concerned with the overall delivery of this care. Finally we will close with reflection on the potential areas for future development that will ultimately aim to improve long-term outcomes and experiences of the young adolescent confronted with diabetes as well as the burden of disease and burden of cost of disease.

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Core tip: This manuscript is a comprehensive review of the challenges encountered during the transition of diabetes care from paediatric to adult diabetes services. Further we explore the structured transitional programs that could help in the smooth transition of diabetes care from the youth to early adulthood.

Abstract

Diabetes mellitus is a complex condition with far reaching physical, psychological and psychosocial effects. These outcomes can be significant when considering the care of a youth transferring from paediatric through to adult diabetes services. The art of mastering a smooth care transfer is crucial if not pivotal to optimising overall diabetic control. Quite often the nature of consultation varies between the two service providers and the objectives and outcomes will mirror this. The purpose of this review is to analyse the particular challenges and barriers one might expect to encounter when transferring these services over to an adult care provider. Particular emphasis is paid towards the psychological aspects of this delicate period, which needs to be recognised and appreciated appropriately in order to understand the particular plights a young diabetic child will be challenged with. We explore the approaches that can be positively adopted in order

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INTRODUCTION

Adolescence is a term derived from the Latin word, “to grow up”^[1]. Not only does it denote a transitional phase of physical change and maturation, but also an immense modification of patient psychology. The presence of chronic long term illnesses such as type 1 diabetes may make this vulnerable group even more prone to fall out of the healthcare system and be prone for development of acute or chronic complications.

Diabetes is a complex condition that patients of all

ages often struggle to manage, as it requires many adaptations and modifications to lifestyle. It is often a great challenge when we take into consideration the physical, social and psychological interactions that a young adolescent is often faced with^[2]. The scope for development in this area remains vast and the need for a structured framework paramount^[3]. The diabetic consultation also changes in a way, from being initially a complex, dynamic parent-led interaction to being a physician-led shortened purpose driven appointment. The lack of this assumed comfortable niche may often leave the adolescent with diabetes feeling abandoned and thus susceptible to poor diabetic control and its complications. The purpose of this article is to highlight the importance of a structured transitional program that could help to alleviate some of the challenges of this turbulent process and help to enable a swift transition from early youth to emerging adulthood.

The key aspects to focus in this review are assessing risks of developing poor glycaemic control during this period, risk of potential complications, acute vs chronic as well as possible ways of engaging this at-risk vulnerable cohort of patients. We explore the potential implications of transition from paediatric to adult services and the potential processes that could be considered for service development and also to enhance the patient journey.

THE SCOPE OF THE PROBLEM

The proportion of young adults under the age of 20 years affected by diabetes in 2010 was 0.26%^[4]. The “search for diabetes in Youth” study estimated that on average approximately 15000 youth are diagnosed with type 1 diabetes and 3700 with type 2 diabetes annually in the United States^[5]. Given the changes in demographics and society, these numbers are projected to increase year on year and henceforth highlighting the need to be vigilant of the problems young teens face and being able to provide a framework to forward the development of this specific aspect of adolescent care^[6,7].

The other key feature to be alerted to when accounting for this cohort of patients is the projected increase in the childhood onset of type 2 diabetes^[8]. As sedentary lifestyles become more common and fast food more readily available thereby propelling obesity incidence, the emerging numbers of type 2 diabetics is ever more a problem we will encounter in clinical practice^[9]. This would therefore cascade down to increasing numbers of adolescents with diabetes who will eventually transition from paediatric to adult care ultimately. The important aspect to be aware of in provision of care for this cohort of patients is to be alert to the changes they will be facing. Thus as any other adolescent will be assuming new roles and changing identities, this is no less apparent in adolescents with diabetes mellitus. The transition services therefore needs to be adapted accordingly and the clinician needs an appreciation of the complexities the youth

will be challenged with in general, but more so particularly in the setting of diabetes mellitus.

MODELS OF DEVELOPMENT

There are various psychological models of development that have been put forward to explain the key stages in a young adolescent's life^[10]. It is pertinent to be aware of these theories in order to tailor our approach and modify these according to the stages of development. Ignorance of these changes of roles may lead to the provision of sub-optimal care and hence ultimately compromise diabetic control and leave the youth prone to complications, both in the immediate and longer term.

A model of impact of personal change that reflects the changes the young adolescent individual experiences has been previously proposed^[10]. The model has a useful analogy to the changes a young adolescent would experience when transitioning of their diabetic care^[11]. There is an initial excitement and almost “honeymoon” phase where the young youth is coming of adulthood and excited to be leaving paediatric services, only to gain autonomy of their own care. However this is later followed by a sense of confusion and lack of confidence and almost a crisis stage. Alongside understanding theories of development and change it is also critical to appreciate and understand the corresponding psychosocial changes the youth will be greeted with. This period of emerging adulthood is often the period of most change where young children are assuming new roles of education, moving out of the parental home and progressing towards seeking employment and independence. It is of paramount importance to understand this psychological metamorphosis of a teenager, as it is during this process that the adolescents are most susceptible to run into problems and lack of understanding of this process by the adult care providers acts as a confounding barrier to effective care provision^[12]. Care providers and service managers need to acknowledge this and incorporate necessary amendments in their model of care delivery, without which the care could be disruptive, disjointed and not tailored leading to high fall-out rates^[13].

In many countries, suboptimal outcomes in the management of diabetes in young adults have lead to centralization of diabetes care. With this the optimization of treatment and outcomes is concentrated in such regional centres and centres of excellence, and subsequently used to reach out to comprehensively improve care in all regions. The need for a multi-disciplinary team, the central role of education and the overlying need for better metabolic control depend on such centres. In developing countries, such centres may develop spontaneously based on perceived need for centralized policies and action. In more comprehensive care systems such as in Europe, marginal outcome data force health care providers to redesign diabetes care, which in some countries is resulting in an orchestrated centre development.

Table 1 Changes in the HbA1c during the transition through the joint transition clinics and the young adult clinics (*n* = 65)

	Joint transition clinic	Young adult clinic
Mean entry age (yr)	17.1	18.5
Number of patients per clinic	2.9	2.7
Mean change HbA1c (DCCT HbA1c %)	0.1	0.2
Mean HbA1c entry (DCCT HbA1c %)	9.8	9.7
Mean HbA1c exit (DCCT HbA1c %)	9.7	9.8
Proportion with > 1% HbA1c (DCCT) improvement	25%	19%
Proportion with improvement in HbA1c	49%	50%

DCCT: Diabetes control and complications trial.

CHALLENGES AND BARRIERS IN THE TRANSITION PROCESS

Delivery of care

Perhaps the biggest change in transition of care is mode of delivery^[14]. Initially the child will encounter an aspect of their diabetes care being provided in a very family centered manner, in converse to adult care which is very much assumed and based on the young adult gaining autonomy and identity of their own care, without the parental guidance and support. Different roles and methods have been adopted in the clinical setting to help face and tackle these challenging times^[15].

Emerging evidence is gaining credibility that by providing transitional care based on gradual transition is far more successful and advantageous in terms of outcomes, as opposed to offering a simple transfer to care to services^[16]. This allows the individual to experience a smooth healthcare experience that is free of plentiful turmoil and change. Certain centers have set up a joint transition clinic whereby paediatricians, adult clinicians and specialist diabetic nurses (DSN) from Paediatric and Adolescent services are directly involved in the delivery of care in this potentially vulnerable period.

We report the model of transition diabetes care in our regional tertiary center where the transition process pans out over 6-8 clinic appointments over a typical 24 mo period, staged through Joint Transition clinic and Young adult clinic. Children with diabetes ready for transition are identified by the paediatric diabetes team and reviewed in the Joint Transition clinics. Majority of these children are between 16 and 18 years of age. During the first two reviews the clinic is led by the paediatric team with the adult diabetes Consultant and a DSN from the adult diabetes team sitting in the joint clinics. The adult team leads the clinic in the subsequent 2 visits after which the care is transferred to a young adult diabetes clinic. Young Adult diabetes clinics are run by the same adult

diabetes consultant and adult DSN, provide longer duration of consultation for each appointment, and provide open access to diabetes services through the same named DSN. A telephone reminder service is provided through secretarial staff, to improve attendance rates at these clinics. Each young adult is reviewed 2 to 4 times a year in the Young Adult clinic, for up to 3 years based on clinical needs, before being provisionally transferred to general adult diabetes clinic.

By delivering such a model for transition of care there was an overall significant improvement in attendance rates: 72% attendance rates (of 266 appointments) in the joint transition clinics and 75% attendance rates (of 254 patients appointments) in the young adult diabetes clinic compared to the 45% attendance rate prior to the introduction of this robust pathway.

HbA_{1c} and glycaemic control

The success of a holistic diabetes care can be objectively measured and monitored using glycaemic control as a service indicator. Achievement of target glycaemia in the young adolescent group can be challenging with large studies reporting less than one-third achieving the recommended glycaemic targets^[17].

The glycaemic control in the two clinical settings was assessed as part of an internal audit done at our centre. Table 1 shows the changes in the glycaemia as assessed by the HbA_{1c} with the implementation of the transition model at our centre. The HbA_{1c} improved in half of the cohort in the transition model with an significant portion achieving the glycaemic targets of HbA_{1c} < 7.5%.

Loss to follow up

The competing interest of adolescent life along with it inherent psychological changes lead to non-adherence to the service, which can be easily assessed by non-attendance rates to the clinics. There are inevitably adverse short and long term outcomes of patients that are lost to follow up of care^[18,19], such as increased risk of acute glycaemia related complications like DKA and severe hypoglycaemia, long term damage to end organs by way of diabetic retinopathy, nephropathy and longer term cardiovascular damage^[20]. Patients who are lost to follow up have higher risk of hospitalisation with its huge health care cost implications and increased risk of all-cause mortality^[21,22]. Henceforth, various strategies of improving attendance need to be put forward and implemented to improve adherence to the service.

Various centers have devised methods to tackle and approach the above obstacle and have found that use of a simple text reminder service to remind patients of clinic appointments will help them engage with services better thereby helping with improving long term outcomes^[23].

At our centre, introduction of a simple telephone service made a significant impact on attendance rates at these clinics. A non-medical staff member of the team (medical secretary) made a phone call 2-3 d prior to the appointment, with the sole purpose of establishing con-

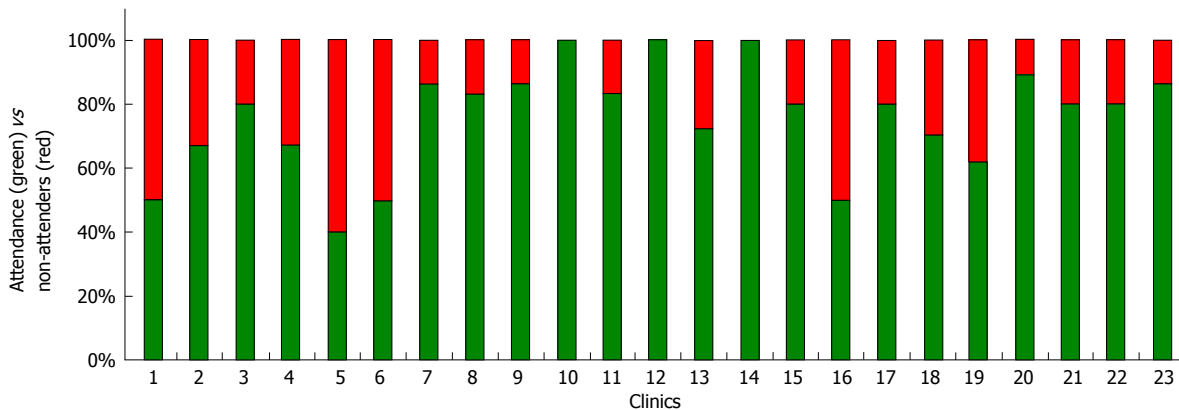


Figure 1 Attendance and non-attendance rates before and after introduction of the telephone service in the young adult clinics^[1]. The telephone reminder was 2 d prior to the appointment (clinic 7 onwards, except clinic 16 and 19) significantly improved attendance rates compared to clinics without it.

Table 2 Impact of the telephonic service on the non-attendance rates in the young adult diabetes clinics

Non-attendance rates	Before telephonic intervention (6 clinics)	With telephonic intervention (15 clinics)
Overall non-attendance rate (%)	41	15
New patient (%)	47	8
Follow up patients (%)	30	19

tact and providing a reminder of the forthcoming appointment. The non-attendance rates were reviewed in 23 clinics-6 clinics pre introduction of telephone service and 17 clinics post introduction of the service of which in 2 clinics the service was not used (due to leave of the staff involved and this was effectively a reality check *per se*). There was a significant reduction in non-attendance rate with the introduction of the telephone reminder, both for new and follow-up patients (Table 2). The two of the 17 clinics which did not have this service since the introduction of the process, showed significantly higher non-attendance rates (50% and 38%) thereby internally proving the value of the appointment reminder service and emphasizing how prudent it can be in enhancing attendance to the young adult diabetes clinic (Figure 1). The introduction of a simple telephone service to remind patients of their clinic appointments therefore proved to be a simple addition to improve efficient utilisation of clinic time and in the longer run could demonstrate to be significantly cost effective.

Psychosocial stressors as barriers

Young adults with diabetes are also more likely to face psychological issues hindering their care and management, as evidenced by any patients challenging chronic long-term conditions^[24,25]. Thus efficient delivery of care is crucial to allow for this vulnerable patient group in a susceptible period where their lives are simultaneously changing.

Depression in diabetes is a recognised co-morbid factor and will increase mortality and leads to poorer gly-

caemic control^[26]. Up to 33% of adolescent's aged 18-30 years will report depressive symptoms^[27]. It is also important to be vigilant of the high risk of eating disorders and substance misuse and insulin misuse, with the risk of misusing insulin for unhealthy weight control measures being quoted to be as high as 57%^[28,29].

In our transition clinic setting all patients have access to psychological support from the clinical psychologist embedded in the diabetes team. Some patients are specifically referred to psychology if the teams have any concerns. Authors believe such a model is efficient way of utilization of resources and can be easily replicated across the globe.

Sexual and reproductive health

Unplanned pregnancy remains a major problem in teenagers with co-existing diabetes. The use of contraception has been found to be lower in patients with diabetes (39%) as compared to those without (27%)^[30]. Issues around contraception need to be proactively addressed at the young adult diabetes clinics, with emphasis on pre-conception counseling and optimising diabetes care to improve fetal and maternal outcomes^[31]. This again highlights the multitude of dimensions that the consultation at the young adult clinic needs to take and address numerous additional challenging issues that young teens will now face.

RECOMMENDATIONS TO IMPROVE MODELS OF CARE

It is therefore prudent that the transition care for children with diabetes should be structured, coordinated with a multi-disciplinary approach with collaboration and communication between the paediatric and adult diabetes teams and making sure the young adult's care is effectively taken over by the adult diabetes team with prior engagement in conjunction with the paediatric team. Despite the clear need for such systematic transition there appears to be lack of a structured approach to this provision and delivery of successful care to provide a service

that is multifaceted and enables the interactions to occur in a step wise fashion allowing the gentle introduction of adult services and gradually stepping away from paediatric input.

Young adults with diabetes, as with any teenage child facing a chronic long term condition, are more vulnerable to the changes of adaptation in care and hence there is greater risk of this care being compromised at a time where they need it most and at a time where the longer term complications (as well as acute) need to be screened and monitored for^[32]. One key obstacle identified here is the loss to follow up of these patients. There is evidence to support the use of a simple telephonic calling system in order to aid compliance and concordance with the adult services and ultimately improve outcomes, reduce long-term complications and reduction of end point mortality.

There is evidence that structured transition processes improve health outcomes and quality of life. International organizations including American Diabetes Association, International society for pediatric and adolescent diabetes, Diabetes United Kingdom recommend a structured framework of goals to be outlined and met when transition care of young diabetics to adult services^[33-35]. There are no proven uniform strategies to achieve all these goals, although programs that particularly target the young adult with diabetes through education, skills training, specialty transition clinics, or addition of transition coordinators may help towards achieving such goals, for this rising global challenge^[36]. It is therefore pivotal that every effort is made to encompass all aspects of their care which will be instrumental in designing and developing a joint care pathway for young adults emerging into adulthood for a well-recognized but less commonly perceived problem in routine clinical practice in the world of diabetes.

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