

Adolescents with Type 1 Diabetes and the Paediatrics Diabetes Clinic

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Aim

This report aims to characterise the adolescent population with T1D attending University Hospital Limerick (UHL) paediatric diabetes services and carry out subgroup analysis of high-risk patients.

High-risk are those with HbA1c \geq 75mmol/mol(9%) and factors impacting disease management including psychosocial issues/other chronic diseases.

Methods

Data was collected using Microsoft Excel, from adolescents attending UHL paediatric diabetes clinic and age \geq 14 years between January 1st-June 30th 2022, and analysed using Excel, Minitab and OpenStax.

Results

74 adolescents, equal males and females, of whom 20 were high-risk, were included. High-risk individuals were less likely to use insulin pumps or continuous glucose monitoring devices, and more likely to have lipohypertrophy than non-high-risk peers. Of those high-risk, 6 had at least one consultation with a medical social worker (MSW) (1 of these had another chronic disease and saw MSW dedicated to this disease-team) and 14 had at least one consultation with a paediatric clinical psychologist. There is a clear deficit of MSW and paediatric psychology input in the management of these adolescents.

Conclusion

Active screening for diabetic control risk factors as well as appropriate funding to support team-specific MSW and psychology input for high-risk patients is urgently required to meet current best practice guidelines.

Introduction

Transition from paediatric to adult care is a phase of potential challenges including decrease in glycaemic control, decreased clinic attendance and an increase in diabetes-related complications, all during a phase of increased physiological insulin resistance(1)(2). Transition between paediatric and adult care models is aided by the provision of ‘transition clinics’, linking multidisciplinary care across a team of paediatric and adult consultant endocrinologists, dieticians, diabetes specialist nurses as well as paediatric-trained medical social workers (MSW), clinical psychologists, diabetes podiatrists and advanced midwife

practitioners. Optimising diabetes control prior to transition is fundamental in ensuring smooth transition. The UHL diabetes transition service underwent redesign between 2017 and 2020, currently having ongoing input from all the above disciplines, with the notable absence of diabetes MSW and minimal access to clinical psychology, due to resource deficiencies.

This paper aims to characterise the adolescent population living with T1D attending the UHL paediatric diabetes clinic and to carry out a subgroup analysis of high-risk patients. High-risk patients were identified by HbA1c levels ≥ 75 mmol/mol (9%) and/or particular psychosocial factors/risky behaviours affecting their diabetes management. Risky behaviours include decreased adherence to disease management protocol, decreased clinic attendance and issues with self-management related to documented social and psychological issues. A dynamic list of adolescents meeting these criteria was created during the COVID-19 pandemic as a surveillance mechanism to target high-risk patients requiring frequent contact and MDT support. This list is reviewed 1-2 monthly. It is noteworthy that UHL serves a catchment area containing 7 out of the 10 lowest decile socioeconomic areas nationally³.

All individuals included were ≥ 14 years before January 1st 2022. The general adolescent T1D population comprised 74 young people, of whom 20 were on the high-risk list during the study period (January 1st to June 30th 2022).

Methods

This study analyses prospectively collected data from the UHL paediatric diabetes clinic, with supplemental data collected retrospectively. Participants were recruited from the T1D adolescent population. All participants consented to data collection and analysis.

Data collection included patient sex, date of birth, date of diagnosis, DKA status at admission, other medical conditions subsequently or previously diagnosed, most recent HbA1c and whether lipohypertrophies were present. Information regarding socio-demographic data was collected from diabetes specialist nurses but was restricted to high-risk list inclusion. Information on insulin regime including CSII and CGM usage was collected. If patients were not using a CSII device, the number of daily insulin injections was collected. HbA1c was used as the primary marker of disease control quality². Hospitalisation during the study period was collected.

Data was entered anonymously into an Excel database for analysis using Introductory Statistics (OpenStax) and Minitab. Two Sample-T test was used for continuous data and Z-Test for binary data. Data were compared between those on the at-risk list and those not during the study period. Significance was accepted as $p < 0.05$.

This study received ethical approval from the local institutional research ethics board.

Results

	Whole N=74	Standard N=54	High-risk N=20	
<i>Continuous Subcutaneous Insulin Infusion Regime (CSII or Pump)</i>	22/74	20/54	2/20	p=0.02 S
<i>Multiple Daily Injections of Insulin</i>	52/74	34/54	18/20	p=0.01 S
<i>Continuous Glucose Monitor (CGM)</i>	51/74	43/54	8/20	p=0.02 S
<i>HbA1c</i>	68.53±17.23 mmol/mol 8.4±3.7%	62.70±11.69 mmol/mol 7.9±3.2%	84.25±19.56 mmol/mol 9.8±3.9%	p = <0.01 S
<i>Age (years, mean ± standard deviation)</i>	16.70±1.63 years	16.72±3.47 years	16.03±1.29 years	p = 0.06 NS
<i>Diabetic Ketoacidosis (DKA) present at the time of diagnosis</i>	42/74	30/54	12/20	p = 0.73 NS
<i>Presence of other medical co-existing diagnoses</i>	26/74	18/54	8/20	p= 0.59 NS
<i>Presence of diagnosed other auto-immune conditions</i>	20/74	16/54	4/20	p = 0.41 NS
<i>Average age at Diagnosis (years, mean ± standard deviation)</i>	10.37±3.44 years	10.55±3.55 years	9.94 ±3.71 years	p = 0.53 NS
<i>Average Duration Diagnosis (years, mean ± standard deviation)</i>	6.28±3.58 years	6.10±3.47 years	6.11±4.19 years	p = 0.99 NS
<i>Lipohypertrophies</i>	20/74	10/74	10//20	p =0.01 S
<i>Sex</i>	37 Male 37 Female	27 Male 27 Female	10 Male 10 Female	

Table 1: UHL adolescents both high-risk and standard cohorts as of June 30th 2022

Primary Reason for inclusion in high-risk list	
High HbA1c	18/20
Social	1/20
Other	1/20

Table 2: Reasons for UHL adolescents on deemed high risk as of June 30th 2022 (20 patients)

HbA1c levels were higher in the high-risk cohort, corresponding to the predominant indication for high-risk list inclusion, i.e. high HbA1c (90%).

27% of adolescents used continuous subcutaneous-insulin infusion or “pumps” (CSII) (Table 1). 37% of the standard cohort used CSII compared to 10% of the high-risk group ($p=0.024$). The remainder used multiple daily insulin injections (MDI). The average number of injections used averaged 3.8 injections daily (Table 1).

40% of high-risk patients use continuous glucose monitors (CGMs), compared to 80% of the standard cohort ($p=0.024$). CGM usage is electively chosen by the patients and both groups had equal access to this choice.

Of adolescents using CGMS, 66% used Libre devices, with the remainder using Dexcom ($p=0.02$).

There was no difference in DKA at first presentation of T1D.

35% of the total adolescent group had co-existing medical conditions. 27% were auto-immune related: the most common being hypothyroidism (45%) and coeliac disease (40%). There was no statistical difference between groups.

No statistical difference was observed in either average age of diagnosis or duration of diagnosis.

Lipohypertrophies are common skin complications associated with non-rotation of insulin injections. 27% of all adolescents had evidence of lipohypertrophy at their last outpatient appointment. Lipohypertrophy was more common in the high-risk group ($p=0.01$).

6/20 high-risk list individuals were hospitalised during the study period. 5/6 were admitted due to diabetes issues – namely, hypoglycaemic episodes. 1/6 was admitted in relation to another chronic disease.

High-risk list referrals to medical social work (MSW) were identified retrospectively. 6/20 high-risk individuals had consultations with MSW during the study period. 1 had another chronic disease and saw MSW dedicated to that particular care team. The 5 remaining

individuals saw MSW during hospital admission for their diabetes care. There was no outpatient MSW support available. Thus 15/20 high-risk patients were not seen by MSW. MSW is part of the holistic support given to those struggling with high HbA1c and is done as part of a complete inpatient workup including psychologist referral.

High-risk adolescents receiving at least one consultation with paediatric clinical psychology were identified retrospectively. 14/20 individuals were referred to psychology while on the high-risk list. This was due to issues highlighted by the diabetes team at outpatient clinics due to social factors, namely poor home support, anxiety and issues with disease management. 6/20 were not seen by clinical psychology during the study period.

Discussion:

Management of type one diabetes (T1D) is complex, multi-disciplinary and places a high burden of care on the adolescent^{2,4,5}.

Transition from adult to paediatric care occurs at a time when there is already a large number of situational (leaving secondary school, diabetes autonomy, moving to university) and developmental changes in a young person's life^{6,2}. By characterising the adolescent T1D population, we can better account for these changes and aim to improve transition care¹. Improved transition is essential to better disease control and results in lower diabetes-related complications⁵. Adolescents with T1D face anxiety and stress at the impending transition as they approach adulthood which can be mitigated by ensuring smooth transition care^{5,7}. The first step is to understand the population involved. This study characterises the adolescent population with T1D attending UHL and highlights the large high-risk cohort within this group, highlighting the need for better psychological and MSW support for these patients.

The high-risk list was created during the COVID-19 pandemic as a surveillance mechanism for empowering contact between high-risk T1D adolescents and the paediatric diabetes multi-disciplinary team.

There have been multiple benefits to the creation of this group, most markedly the improved contact with and identification of high-risk individuals. It is notable that 27% of UHL adolescents were identified as high-risk during the study period. This is indicative of the biopsychosocial burden of T1D on adolescents, and likely represents the socio-economic deprivation in the catchment area of UHL as discussed³. Inclusion to the high-risk list arises due to high/unstable HbA1c levels and psychological/social issues experienced by the patient. It aims to identify the cohort for whom diabetes-related complications, psychological problems and frequent hospitalisation are more likely. Currently, access to MSW and clinical psychology support is reserved for those identified as struggling significantly (and admitted to hospital). It would be interesting to see if regular access to adequate out-patient MSW and clinical psychology support, as per HSE model of care recommendations, would result in decreased numbers on the high-risk list⁵.

High-risk individuals were nominated as high-risk for a variety of reasons, including psychosocial, high HbA1c, and co-existing serious medical conditions. The majority of

individuals (90%) were identified due to high HbA1c levels, a major risk factor for developing diabetes-related complications^{8,9,10}. While on the high-risk list, improved and more frequent contact is achieved through regular phone calls with the diabetes nurse specialists, ongoing age-appropriate education, support and follow-up.

HbA1c level is a measure of glycated haemoglobin and shows the average blood glucose level over the past 90 days¹. It can be used as an indicator of future diabetes-related complications risks and mortality¹¹. HbA1c levels were significantly higher ($p=0.02$) in the high-risk cohort, making them more at risk for diabetes-related complications¹². The high proportion of high-risk individuals deemed so due to high HbA1c levels is concerning. Identifying these individuals prior to transition is beneficial in maximising care-benefit prior to entry to adult services and in identifying key issues to be addressed at transition clinics.

The use of insulin pumps allows for precise insulin administration and reduces the number of injections given¹². Insulin pump therapy (CSII) attempts to mimic normal physiological insulin secretion, allowing greater glycaemic control¹². Insulin pumps were used by 27% of the adolescent population in this study, although only 10% of the high-risk list individuals used them (significant $p<0.005$). With increasing use of hybrid closed loop systems, it is likely that future studies will demonstrate increased initiation of CSII, including in adolescents with high HbA1c.

57% of the total adolescent cohort were diagnosed in diabetic ketoacidosis (DKA). Previous studies suggest that diagnosis in DKA is a determinant of future glycaemic control and found to be associated with higher HbA1c levels in the years following diagnosis¹³¹⁴. In this paper, no difference was seen across high-risk and standard cohorts in regard to diagnosis in DKA. The high percentage of children and adolescents diagnosed in DKA is concerning. Future studies may investigate the possibility of both addressing and comparing this to other countries. Perhaps public service announcements and advertising campaigns addressing early signs and symptoms may be of use in ensuring early diagnosis, detection and control of T1D.

T1D is associated with a high prevalence of other auto-immune diseases, particularly coeliac disease and thyroiditis¹⁵. Of the adolescent population in this study, 35% had co-existing medical conditions, 77% of these being auto-immune: most commonly hypothyroidism and coeliac disease. The co-existing diagnosis of such conditions can complicate glycaemic control^{16,17}.

This study also examined the prevalence of lipohypertrophies. Insulin-induced lipohypertrophy is the most common skin issue associated with T1D¹⁸. Not rotating injection sites and multiple injections are two major risk factors¹⁹. In the present study 27% of adolescents had lipohypertrophies at time of last OPD appointment. Of these 50% were high-risk ($p=0.01$). With the advent of hybrid closed-loop CSII, it is likely that the number of high-risk T1D adolescents using CSII will increase in the future and care providers need to be educated on the potential risks and benefits of this.

UHL has no dedicated paediatric diabetes MSW service and little paediatric clinical psychology support for those diagnosed. Ongoing dedicated psychology and MSW support is recommended for all children and adolescents with T1D. The study highlights that there is a great need for this support, especially in the 27% of high-risk adolescents. All of these should have received dedicated MSW and psychological support during the study period in line with HSE policies²⁰. The key finding from the 6 high-risk individuals referred to MSW during the course of the study is that at UHL, users of the paediatric diabetes service can only access MSW support once they are admitted to hospital. This is at variance with HSE policies, where ongoing interaction with MSW is a recommendation^{5,11}. The glaring anomaly in this study is the fact that 90% of the patients deemed high-risk were deemed so due to high HbA1c levels. 14 individuals were ascertained to be eligible for psychological referral due to psychosocial factors at time of high-risk inclusion including anxiety, poor home support and struggles with disease management, although this was not the primary reason for their inclusion. There is at present no out-patient access to MSW. This has been placed on the UHL hospital risk register.

During the study period, 27% of T1D adolescents attending UHL paediatric diabetes clinic were deemed to be high-risk. The lack of dedicated paediatric psychology and MSW support is a concerning factor in light of same. This inequitable access should be addressed and this study repeated to explore the effects of adequate and appropriate psychology and MSW support in this vulnerable group. Highlighting high-risk groups and characterising the adolescent population paves the way for both more effective transition care and better awareness entering the adult care system. This study highlights that investment in out-patient MSW and psychological support for paediatric diabetes is required and its absence is a contributory factor to high levels of diabetes distress and poor diabetes control in T1D adolescents as they transition across care services.

Declarations of Conflicts of Interest:

None declared.

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