

Young adult type 1 diabetes care in the West of Ireland: an audit of hospital practice

R. CASEY^{1,2}, M.C. O'HARA^{1,2}, A. CUNNINGHAM^{1,3}, D. WALL³, R. GEOGHEGAN⁴, L. HYNES⁵, B. McGUIRE⁵, M. GATELY¹, M. BELL^{1,2} and S.F. DINNEEN^{1,2}

From the ¹Endocrinology and Diabetes Centre, Galway University Hospitals, Galway, Ireland, ²School of Medicine, NUI Galway, Galway, Ireland, ³School of Mathematics, Statistics and Applied Mathematics, NUI Galway, Galway, Ireland, ⁴Department of Paediatrics, Galway University Hospitals, Galway, Ireland and ⁵School of Psychology, NUI Galway, Galway, Ireland

Address correspondence to Dr R. Casey, Department of Endocrinology, Galway University Hospital, Galway, Ireland. email: ruthcasey232@gmail.com

Received 30 December 2013 and in revised form 29 April 2014

Summary

Background: It is well recognised that management of young adults with type 1 diabetes (T1DM) poses difficult challenges for physicians and health care organisations as a whole. In Ireland and in particular the west of Ireland there has been little audit or research on young adults with T1DM and the services available to them.

Design: In 2011 a retrospective review of this patient population in our territory referral centre was carried out.

Results: The average glycaemic control in this population was poor at 81mmols/mol and diabetes related complications were present in 32%. Engagement by this population with services was poor with an average of 3 missed clinic appointments over a 24 month period.

Conclusion: These results have prompted a re think of how health care professionals can deliver a service that better suits the needs of this challenging patient group.

Introduction

The management of young adults with type 1 diabetes (T1D) poses a number of challenges for both healthcare workers and healthcare organizations. These challenges extend beyond the realm of chronic disease management and therapeutics, to include the psychological and behavioural aspects of chronic illness for young adults.

Adherence to treatment recommendations and good diabetes self-care behaviours improves glycaemic control.^{1,2} Self-management education programmes such as Dose Adjustment for Normal Eating (DAFNE) help individuals improve their self-management skills.³ Failure to comply with diabetes self-care particularly in early adulthood may be a reflection of poor psychological adaptation to

chronic illness and it has been shown that young adults with sub-optimal glycaemic control are more likely to have psychological, emotional or behavioural disorders.⁴ Missed clinic appointments are a common occurrence^{5,6} and Emergency Department (ED) attendances are often high among this group.^{7,8}

It is estimated that between 16 000 and 18 000 people in Ireland have T1D.⁹ The lack of a national diabetes register makes it difficult to know how many of them are young adults, the Institute of Public Health refer only to the 'over 20 years of age' population and these are estimates based on 2007 census figures. In Ireland, and in particular, the West of Ireland, there has been little audit or research on young adults with T1D and the services available to them.

In 2003 a diabetes clinic dedicated to the care of young adults was established in Galway University Hospitals (GUH) in the West of Ireland. Numbers booked into the 'young adult' clinics are smaller to allow more contact time with healthcare professionals. Doctors, nurses and dieticians, who have a special interest in this population staff clinics, and a clinical psychologist are available during clinic visits. The clinic is held once a month on a weekday. Despite this initiative, healthcare professionals delivering care to young adults felt the clinics were not impacting on attendance rates and diabetes outcomes for this group. In October 2011 a group of doctors (from both Paediatrics and adult diabetes services), nurses, dieticians and health and clinical psychologists came together to discuss how this service is delivered. The first step was to conduct a rigorous audit of our young adult service.

Aims

- (i) To determine attendance rates at a dedicated young adult diabetes clinic and whether poor attendance is a predictor of adverse outcomes in this population.
- (ii) To utilize the data collected from the audit to tailor service provision to better meet the needs of this population.

Methods

Setting

The Diabetes Centre in Galway is a stand-alone outpatient department in a university teaching hospital and it serves a large urban and rural catchment area. More than 1000 patients with T1D attend the service and ~5000 patients with type 2 diabetes amounting to more than 26 000 inpatient and outpatient consultations annually.

Design

A retrospective review of the population of young adults (18–25 years old) with T1D in GUH Diabetes Centre was carried out between October and December 2011. Electronic data from three sources were included: (i) a clinical electronic diabetes database (called DIAMOND), (ii) Department of Clinical Biochemistry and (iii) the ED database and records (to provide further information on diabetes-related ED attendance and hospital admissions). Data were collected over a retrospective 24-month period and included information on gender, age, years since diagnosis with T1D, marital status,

method of referral to the adult diabetes clinic, average glycaemic control (assessed by HbA_{1c}), clinic appointments issued and attended, psychology clinics issued and attended, healthcare professional contact time, diabetes-related ED attendances, diabetes-related hospitalizations (including length of stay), diabetes-related complications (such as retinopathy, microalbuminuria and neuropathy) weight (using a Seca® scale), height (using a Seca stadiometer), blood pressure (using a Welch Allyn Dinamap oscillometric device), cholesterol, family history, distance from the Diabetes Centre, smoking status, alcohol units per week (although this was poorly captured by hospital database systems), insulin types and doses (including average number of daily injections and units) and whether or not they have completed a structured education programme such as the DAFNE course (Table 1).

Comparator group

The Scottish Diabetes Survey was selected as the comparator for this audit reported in 2011. It provides a rich dataset of diabetes care and outcomes for Scotland with breakdown by diabetes type and age.

Statistical analysis

Statistical analysis was carried out using SPSS version 18. The reported data are expressed as mean (\pm standard deviation (SD)) unless otherwise stated. Descriptive analyses were conducted to profile the audit population. Several analyses were performed to compare the relationship between glycaemic control and (i) clinic attendance, (ii) ED attendance and (iii) hospital admissions. One-way ANOVA, two-sample *t*-tests, chi-square tests and Spearman and Pearson's correlations were used to determine association and comparisons between groups. *P*-values <0.05 were considered statistically significant.

Results

A total of 137 young adults met the inclusion criteria for the audit. Characteristics of the cohort are described in Table 2. The mean (SD) age was 22 years (1.96), 52% were male, mean duration of diabetes was 9.5 years and 45% were living with T1D for at least 10 years. See Table 3 for antropometric measurements.

Insulin regimen

The use of continuous subcutaneous insulin pump infusion was low (4% of the cohort). The vast

Table 1 Variables of interest used in the review and the original data source

No	Variable	Source	Units
1	Year of diagnosis with type 1 diabetes	DIAMOND	Year(s)
2	Gender	DIAMOND	Male/female
3	Age	DIAMOND	Year(s)
4	Marital status	DIAMOND	Married/separated/single/cohabiting/widowed/divorced
5	Smoking status	DIAMOND	Smoker/never/ex-smoker/occasional
6	Occupation	DIAMOND	
7	HbA _{1c}	Laboratory value	mmol/mol and %
8	Number of diabetes clinic appointments issued and attended	DIAMOND	Number
	Number of retinopathy appointments issued and attended	DIAMOND	Number
	Number of psychology appointments issued and attended	DIAMOND	Number
	Number of contact time(s) with nurse specialist – either telephone or appointment	DIAMOND	Number
	Distance from Diabetes Centre (extrapolated from address)	DIAMOND	km
9	Number of diabetes-related hospitalization	ED database	Number
10	Reason for diabetes-related hospitalization	ED database	Hypoglycaemia/DKA/other
11	Weight	DIAMOND	kg
12	Height	DIAMOND	cm
13	BMI	DIAMOND	kg/m ²
14	Systolic blood pressure	DIAMOND	mm/Hg
15	Diastolic blood pressure	DIAMOND	mm/Hg
16	Triglycerides	Laboratory value	mmol/l
17	Total cholesterol	Laboratory value	mmol/l
18	HDL-cholesterol	Laboratory value	mmol/l
19	LDL-cholesterol	Laboratory value	mmol/l
20	Creatinine	Laboratory value	μmol/l
21	Type of diabetes-related complication	DIAMOND	Hypertension/MI/coronary revascularization/peripheral revascularization/CVA/painful neuropathy/foot ulcer/amputation of toe/amputation above toe level/retinopathy/Laser Rx/registered partially blind/ registered blind/microalbuminuria*/proteinuria**/dialysis/renal transplantation/erectile dysfunction
22	Date of onset of complication	DIAMOND	Date
23	Type of quick acting and background insulin	DIAMOND	Insulin type
24	Average daily dose of quick acting and background insulin	DIAMOND	IU.
25	Average number of injections per day of quick acting and background insulin	DIAMOND	Number
26	Use of insulin pump	DIAMOND	Yes/no
27	Referral source	DIAMOND	Paediatrics, GP, other specialist service, other
28	Date of referral to diabetes centre in Galway	DIAMOND	Date
29	Completion of DAFNE	DIAMOND	Yes/no

BMI, body mass index; LDL, low density lipoprotein; HDL: high density lipoprotein; CVA, cerebrovascular accident; MI, myocardial infarction.

Table 2 Characteristics of study population ($n=137$)

	$n=137$
Age	22.9 (SD 1.96)
Gender	
Male	71 (52%)
Female	66 (48%)
Insulin regime	
MDI	120 (88.9%)
Pump	4 (2.9%)
Pre-mixed insulin	2 (1.4%)
Missing	5 (3.6%)
Referrals	
Paediatric Department	76 (57.6%)
GP	13 (9.8%)
New diagnosis from ED	21 (15.9%)
Other specialist service	22 (16.7%)
No of clinics offered	7.2 (SD 4.2)
No of clinics attended	4.3 (SD 3.1)
Hba1c	9.6 mmol/mol (SD 2.2)
Complications	
Yes	46 (35%)
No	91 (65%)
Microvascular	
Retinopathy	26 (19%)
Microalbuminuria	8 (5.8%)
Proteinuria	1 (0.7%)
Macrovascular	
Hypertension	4 (2.9%)

majority were on a multiple daily injection insulin regimen (90%). A further 2% were on pre-mixed insulin and information was not recorded for 4%. A total of 23% patients had completed a DAFNE course and were matching their quick acting insulin doses to their carbohydrate intake.

Source of referral

The majority of young adults (57%) in our audit were referred from the Paediatric Department in GUH. General Practitioner referrals accounted for 10%, 16% were referred with a new diagnosis following an ED attendance and 17% were referred by another specialist service.

Appointment attendance

Young adults, on average, were offered seven clinic appointments over 24 months but only attended 4 (± 3.1). Patients were listed as 'defaulters' on our diabetes database if they failed to attend any clinic appointment in over 2 years. On average patients were offered two nursing contacts for education over the audit period (range 0–11). In the population audited 12.4% were listed as 'defaulters'. For

Table 3 Average antropometric and biochemical measurements of study cohort

Characteristics	Unit (\pm SD)
Age (years)	22 (2)
HbA _{1c} (%)	9.6 (1.9)
HbA _{1c} (mmol/mol)	81 (14.4)
Blood pressure (mm/Hg)	124/75 (1.2)
BMI (kg/m ²)	25.3 (4.2)
Total cholesterol (mmol/l)	3.4 (2.4)
LDL (mmol/l)	1.4 (2.2)

BMI, body mass index; LDL, low density lipoprotein.

patients with T1D the local recommendation is to have a retinal photograph taken and screen annually. In this study 96% of patients had an annual retinal screen and only 4% of patients did not attend for an annual screen. Of the small percentage of patients who did not attend annually for retinal screening (4%, $n=3$), the longest interval without a retinal screen was 20 months.

Glycaemic control

The average HbA_{1c} measured over a 24-month period was 81 mmol/mol (9.6%). Minimum and maximum values ranged from 43 mmol/mol (6.1%) to 183 mmol/mol (18.9%).

Complications of diabetes

Diabetes-related complications were documented as present in 32% of our population. The most common complication was retinopathy (19%). Among patients with retinopathy 19% were receiving laser therapy. Microalbuminuria was documented in 5.8% of the young adults, 0.7% met the criteria for proteinuria and 2.9% had documented hypertension. One death was recorded in a female patient who had attended our service on one occasion during the audit period.

ED attendances

We analysed ED attendance and hospital admissions in a subgroup ($n=65$) of young adults living within 80 km of GUH. Attendances to ED with Diabetic Ketoacidosis (DKA) at first diagnosis of diabetes were excluded from the analysis. Patients living more than 80 km away were also excluded as they were more likely to attend EDs in other regional hospitals. Of the 65 young adults included, 74% ($n=48$) had at least 1 ED attendance, 46% had 2 or more and 26% had 3 or more attendances.

ED attendance

DKA was the cause of ED attendance in 55.4% ($n=36$) with an average length of stay for patients admitted with DKA of 2 days. Three patients attended ED with severe hypoglycaemia and nine patients attended for treatment of both hypoglycaemia and DKA over a 4-month period. The average length of stay for patients admitted with severe hypoglycaemia was 2 days. Longer duration of illness was associated with more frequent ED attendances with hypoglycaemic events ($P<0.01$).

Associations

There was no statistically significant association (using Pearson correlation) between average HbA_{1c} and missed clinic appointments ($P=0.56$), hypoglycaemia-related ED attendance ($P=0.086$) or DKA-related ED attendance (0.176). There was no significant association (using two-sample *T*-test) between complication status (yes or no) and HbA_{1c} ($P=0.07$). There was a statistically significant relationship between missed clinic appointments and the number of nursing contacts made ($P=0.04$). There was neither any relationship (Pearson correlation) between total ED attendances and missed clinic appointments ($P=0.33$) nor was there a relationship ED attendance and risk of complications ($P=0.5$).

Comparison to Scottish diabetes survey

Figure 1 illustrates the glycaemic control of this cohort compared with 14 other NHS boards

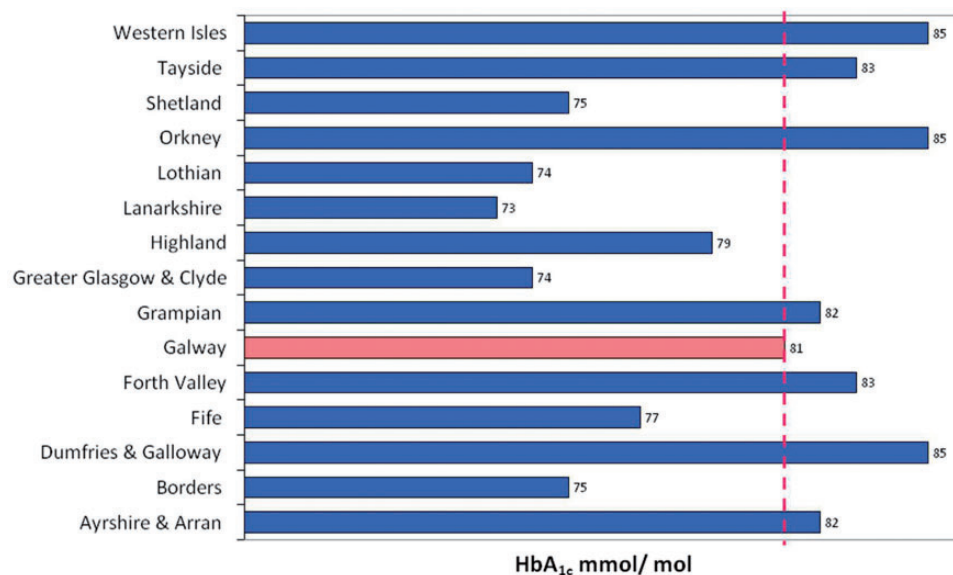


Figure 1. Comparing average glycaemic control of this study cohort to the age-matched (20–24 years) cohort in the Scottish diabetes survey.

included in the Scottish Survey. Average glycaemic control was comparable to a large Scottish cohort (Figure 1). Screening standards were also comparable with 98.4% of patients in our centre being tested for glycaemic control in the previous 24-month period compared with 86% in a 15-month period in the Scottish cohort. On average we were measuring and recording blood pressure in 79.5% of our young adult cohort compared with 85.5% in the Scottish cohort, 79.5% had cholesterol testing compared with 89.2% in the Scottish cohort. Smoking status was very poorly documented in our records and a smoking history was only accounted for in 20% of cases. Retinal screening was offered every 24 months to a 100% of patients with 73% attending scheduled appointments, compared with 85.6% attendance rates in a 15-month period in the Scottish survey.¹⁰

Discussion

It has been well demonstrated in large epidemiological studies that higher rates of morbidity and mortality occur at a younger age within the T1D population.⁹ A review of this increased mortality was demonstrated in a nationwide study from Scotland that evaluated the risks in adults with T1DM compared with the non-diabetic population. Although the rates of mortality have improved in recent years, the Scottish study confirmed an ongoing association between T1DM and higher cardiovascular mortality rates than the non-diabetic population.

Similar results were also seen in another Irish audit of this population from The Adelaide and Meath Hospital, Dublin, where 54 consecutive patients attending a young adult T1D clinic were reviewed. On average attendance rates at clinic in this study were 53%, with 15% of patients only attending 1 in every 3 scheduled appointments. In contrast, this study did show a relationship between missed clinic appointments and poor glycaemic control. Patients who attended over 50% of scheduled visit had a mean HbA_{1c} of 8.92+1.62% as compared with 9.43+1.88% in patients with an attendance rate <50% ($P=0.32$).¹¹

Although no statistically significant link between poor clinic attendance and poor glycaemic control or vascular complications was demonstrated in our study, poor engagement with services has been identified as a risk factor for mortality and microvascular complications in longitudinal studies and observational studies.^{12,13}

Changes/advances in care since the audit

Since the review, members of the diabetes team have been awarded funding by the Health Research Board in Ireland (Ref: HRA-HSR/2013/316) to conduct a systematic review into studies aimed at improving outcomes for this population and to develop a theoretical framework on which to build an intervention to improve the health and well-being of young adults with T1D. The diabetes team have also started to establish a young adult panel of current users of the service to help guide and co-design the research. It is hoped that this approach will lead to a new way of delivering care to this patient group.

Conclusion

Ensuring that the most effective screening strategies are in place is only useful if patients are availing of that service. In this cohort the patients attended on average 57% of their scheduled clinic appointments and patients were inclined to attend ED for treatment of a crisis with 74% of patients presenting at least once to the ED for treatment.

This suggests a system breakdown which is multifactorial owing to the developmental characteristics of young people and system inadequacies of current service models to engage and retain this population group.

Poor engagement with services is not unique to this study and the provision of an effective service

model can only be achieved by taking into the account the views of the service users.

Conflict of interest: None declared.

References

1. Rhee MK, Slocum W, Ziemer DC, Culler SD, Cook CB, El-Kebbi IM, *et al.* Patient adherence improves glycaemic control. *Diabetes Educ* 2005; **31**:240–50.
2. Bott S, Bott U, Berger M, Muhlhauser I. Intensified insulin therapy and the risk of severe hypoglycaemia. *Diabetologia* 1997; **40**:926–32.
3. Oliver L, Thompson G. *The DAFNE Collaborative. Experiences of Developing a Nationally Delivered Evidence-Based, Quality-Assured Programme for People with Type 1 Diabetes.* John Wiley & Sons, Ltd, 2009:371–7.
4. Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB. Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care* 2001; **24**:1536–40.
5. Dyer PH, Lloyd CE, Lancashire RJ, Bain SC, Barnett AH. Factors associated with clinic non-attendance in adults with Type 1 diabetes mellitus. *Diabet Med* 1998; **15**:339–43.
6. Lawson VL, Lyne PA, Harvey JN, Bundy CE. Understanding why people with type 1 diabetes do not attend for specialist advice: a qualitative analysis of the views of people with insulin-dependent diabetes who do not attend diabetes clinic. *J Health Psychol* 2005; **10**:409–23.
7. Holmes-Walker DJ, Llewellyn AC, Farrell K. A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15–25 years. *Diabet Med* 2007; **24**:764–69.
8. Bryden KS, Dunger DB, Mayou RA, Peveler RC, Neil HAW. Poor prognosis of young adults with type 1 diabetes. *Diabetes Care* 2003; **26**:1052–7.
9. Livingstone SJ, Looker HC, Hothersall EJ, Wild SH, Lindsay RS, Chalmers J, *et al.* Risk of cardiovascular disease and total mortality in adults with type 1 diabetes: Scottish registry linkage study. *PLoS Med* 2012; **9**:e1001321.
10. Scottish Diabetes Survey 2011. *Scottish Diabetes Survey Monitoring Group.*
11. Mahmood WA, Tyner W, Carr M, Gibney J, Moore KB. Survey of attitudes, behaviour and experience amongst young adults with Type 1 diabetes. *Ir J Med Sci* 2010; **157**(Suppl. 13):P52.
12. Borch-Johnsen K, Nissen H, Salling N, Henriksen E, Kreiner S, Deckert T, *et al.* The natural history of insulin-dependent diabetes in Denmark: 2. Long-term survival—who and why. *J Diabet Med* 1987; **4**:211–6.
13. Currie CJ, Peyrot M, Morgan CL, Poole CD, Jenkins-Jones S, Rubin RR, *et al.* The impact of treatment non-compliance on mortality in people with type 1 diabetes. *J Diabetes Complications* 2013; **27**:219.