

Paediatric Type 1 Diabetes in Ireland â Results of the First National Audit

Abstract:

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Abstract

The aim of this study was to describe the services provided for children with type 1 diabetes in the Republic of Ireland, and to identify a baseline from which services and outcomes might be improved. Lead clinicians in 17 of the 19 centres providing paediatric type 1 diabetes care responded to requests for information from 2012 regarding demographics, patient numbers, diagnostics, outpatient management, multidisciplinary team resources, comorbidity screening, transition policy, clinical guidelines, and use of insulin pumps. The total number of patients attending these centres was 2518. Eight centres initiate insulin pump therapy. Insulin pump usage ranged from 0 to 42% of patients attending each centre. Self reported clinic mean haemoglobin A1c ranged from 8.2 to 9.4% (66.1 to 79.2 mmol/mol). Variation existed in guideline availability, frequency of clinic appointments, age of transition and insulin types used. We recommend a national approach to standardising and improving care for these patients.

Introduction

Type 1 diabetes is a chronic condition affecting 5-40 per 100,000 of the paediatric population. The incidence is higher in the United Kingdom, Ireland, and Scandinavia than in most of Central and Southern Europe and is rising, particularly in children aged under 5 years^{1,2,3}. The provision of care for this population requires multidisciplinary input, with the ultimate aims of improving quality of life and reducing long-term diabetes related complications. Improved glycaemic control, measured by haemoglobin A1c (HbA1c), reduces the risk of microvascular complications^{4,5,6}. Poor diabetes control is an important modifiable driver of costs associated with type 1 diabetes care^{7,8}. Increased multidisciplinary team resources correlate with improved glycaemic control. However, this is not a linear relationship and is likely influenced by quality of staff training and clinical experience. Little is known of outcomes for children with type 1 diabetes in the Republic of Ireland, but it is likely that they are similar to the United Kingdom. HbA1c in the UK paediatric population is sub optimal, with only 14.5% of children achieving the target of under 7.5% (58 mmol/mol) in 2009-2010 and 15.8% achieving this in 2011^{9,10}.

International Recommendations suggest a caseload per diabetes nurse specialist of between 70 and 100 patients and suggest that smaller services (with less than 70 patients) should have care delivered by a single consultant¹¹. The attendance of a dietitian at diabetes clinic is also recommended¹². The National Health Service in the United Kingdom has recently developed thirteen key standards of paediatric diabetes care and funding provision is dependent on delivering these standards. Recent investment in children's diabetes services in the United Kingdom has reduced caseloads per diabetes nurse from 147 in 2002 to 92 in 2009¹³ and has improved dietetic access¹². It is anticipated that the identification and implementation of incentivised standards of care will improve outcomes. The most recent review of children's diabetes services in Ireland (2006) identified that 2040 patients attended 29 consultants in 19 centres, with consultant caseload ranging from 25 to 270 patients. Insulin pump therapy was available in 4 centres¹⁴, and only 4% of patients were using this treatment. The average caseload per diabetes nurse specialist was 162 patients¹⁵. National data on HbA1c outcomes in Ireland have never been described.

The aim of this study was to describe the provision and quality of diabetes services for children with type 1 diabetes in the Republic of Ireland, and to establish a baseline from which services and outcomes might be improved.

Methods

An online questionnaire was developed using Survey Monkey (California, USA). This survey requested information regarding demographics, patient numbers, diagnostics, outpatient management, multidisciplinary team resources, comorbidity screening, transition policy, clinical guidelines, and use of insulin pumps. Information was collected for all patients who attended the service during 2012, and mean HbA1c excluded all patients diagnosed after 1st January 2012. Nineteen centres were identified as managing children with type 1 diabetes. The criterion for inclusion as a centre was the attendance of children with type 1 diabetes to the outpatient department for routine diabetes care. A lead consultant was identified in each centre and the survey was sent via email on 18th January 2013, with an initial deadline of 1st March. This deadline was subsequently extended to 9th June 2013. All lead consultants had confirmed contact via email or phone during this time period.

Results

Lead clinicians in 17 out of the 19 identified centres submitted questionnaire responses. In 14 of these centres, mean HbA1c was reported.

Patient Numbers

The total number of patients attending each centre is presented geographically in Figure 1. The numbers reflect the total number of patients who attended each centre at least once in 2012. Where an individual had care shared between two centres, they are counted in both. In the 17 centres that reported data, the total number of newly diagnosed patients in 2010, 2011 and 2012 were 262, 283 and 287, respectively. The number of newly diagnosed patients in each centre ranged from 0 to 37 in 2010, 5 to 41 in 2011 and 5 to 49 in 2012.

Resources

Diabetes nurses and dieticians who were not specifically trained in paediatrics often provided care in smaller centres. Only one centre had appropriate diabetes nurse specialist to patient ratio to meet the recommended 70-100 patients per diabetes nurse (Figure 2), but this centre did not have a dedicated paediatric diabetes nurse specialist. Insulin pump initiation was available in 8 (47%) of the 17 centres. Those centres that did not initiate pump therapy arranged shared care or transfer of care to another centre for this. The number of patients using insulin pumps varied between centres, ranging from 0 to 42% (Figure 3).

Outcomes

15 centres provided self-reported mean HbA1c, and 14 provided these stratified in age categories 0-5.99 years (7.4 to 8.7%, 57.4 to 71.6 mmol/mol), 6-11.99 years (7.9 to 9%, 62.8 to 74.9 mmol/mol), 12-15.99 years (8.1 to 9.6%, 65 to 81.4 mmol/mol), 16-17.99 years (8.2 to 10.2%, 66.1 to 88 mmol/mol) and >18 years (7.2 to 10.4%, 55.2 to 90.2 mmol/mol). The mean clinic average HbA1c ranged from 8.2 to 9.4% (66.1 to 79.2 mmol/mol) and varied geographically. In the North West clinics, the mean self-reported HbA1c were 8.7%, 9%, 9.1% and 9.4% (71.6, 74.9, 76 and 79.2 mmol/mol). In the East and Midlands clinics, these were 8.2%, 8.3%, 8.4%, 8.4%, 8.5%, 8.6% (66.1, 67.2, 68.3, 68.3, 69.4 and 70.5 mmol/mol). In the Southern clinics, these were 8.3%, 8.4%, 8.7% and 8.7% (67.2, 68.3, 71.6 and 71.6 mmol/mol).

Guidelines and Practice

Frequency of outpatient clinic appointments was 3 monthly in 12 (70%), 4 monthly in 3 (18%) and 5 monthly in 2 (12%) centres. Larger centres were less likely to provide the recommended 3 monthly appointments and insufficient resources to provide these for the large patient number was cited as the reason. Written protocols for the management of diabetes ketoacidosis (n=17, 100%), education plan for newly diagnosed (n=16, 94%), sick day rules (n=16, 94%), hypoglycaemia management (n=14, 82%), perioperative management (n=13, 77%), poor outpatient attenders (n=4, 23.5%), children with high HbA1c (n=3, 17.6%) and transition to adult care (n=3, 17.6%) were available. All responders would welcome the development of national guidelines for these listed protocols. The age limit of acceptance of newly diagnosed children with type 1 diabetes under paediatric care was very variable. The age cut off was 14 years in 5 (29%), 15 years in 2 (12%), 16 years in 8 (47%) and 17 years in 2 (12%) centres. Timing of transition of established patients to adult services also varied considerably occurring at 16 years (n= 4, 24%), 17 years (n= 4, 24%), 18 years (n= 5, 28%) or at school completion (n= 4, 24%). The starting insulin type used in newly diagnosed children stratified according to age is shown in Table 1.

Discussion

This is the first study to describe in detail the diabetes services for children with type 1 diabetes in the Republic of Ireland, and it has demonstrated wide variation in the structure and process of care between centres. Specifically, these variations are noted in patient numbers, team resources, initiation of insulin pump therapy, clinical guidelines availability, age of transition and HbA1c outcomes. Despite the limitations of self-reported data, this provides a starting point to establish current care provision and distribution of resources, and to inform future service planning. Children with type 1 diabetes require specialised care, provided by a team with appropriate expertise. Diabetic ketoacidosis is present in approximately one quarter of children at diagnosis¹⁵, which can rarely be associated with life threatening cerebral oedema¹⁶ and appropriate guidelines for management should be followed. All centres that responded to this survey have guidelines for this. Following initial management, structured education should be provided to empower patients and their families in diabetes care¹⁷ and most centres also have guidelines for this. However, only one fifth of Irish centres have guidelines in place for the management of children who fail to attend clinic regularly or have persistently poor glycaemic control, and for adolescents being transitioned to adult care.

The data presented here highlight significant deficiencies across multidisciplinary teams in Ireland. It has previously been identified that many consultants delivering paediatric diabetes care in the Republic of Ireland as part of their⁴ general paediatric workload have no specific training or ongoing Continuing Medical Education in paediatric diabetes⁴. Many services have insufficient diabetes nurses and dietitians and poor access to psychosocial services. High quality care delivery requires trained, adequately staffed multidisciplinary teams. It may be infeasible to provide this multidisciplinary care in smaller centres without sufficient patient numbers to justify the resource. Variation in HbA1c between centres has been reported in other countries¹⁸, and is not unexpected. This outcome measure does correlate with long term risk of diabetes related complications¹⁹, but is not the only factor to be considered when comparing patient groups. Readmission rates with diabetes related illnesses, average length of stay, incidence of severe hypoglycaemia are also measures of service quality. Frequency of diabetic ketoacidosis presentation is associated with higher HbA1c, but severe hypoglycaemia is not²⁰.

Severe hypoglycaemia can occur in up to 40% of patients, and can be associated with seizures or coma²¹. Fear of hypoglycaemia can have a significant effect on parental quality of life and may have a negative impact on glycaemic control^{22,23}. Data on these factors were not collected in this²⁴ audit. Other cardio-metabolic factors such as blood pressure and lipid profile are also likely to affect outcome²⁵.

While this study will inform future paediatric diabetes care in Ireland, the data has a number of limitations. All data is self-reported, and required providers to manually find and input data. Accuracy is challenging in this context and more in-depth data on HbA1c such as medians, and percentages of patients achieving targets was not possible. Shared care of patients between centres is likely to have resulted in a number of patients being counted twice. This represents a small proportion of total patients, but will influence results. A national computerised data management system integrating clinic notes with prospective audit, and allowing for bench marking of outcomes would improve care nationally and this is currently in the early stages of development.

In the context of limited resources, regionalising diabetes care for children with type 1 diabetes should be considered. Large patient numbers are necessary to justify full time employment of a large multidisciplinary team. This would allow for the maintenance of skills, attendance at best practice meetings and improvement in patient care. It would also facilitate skilled out-of-hours coverage as well as emergency cover of sick leave or unexpected absences. While this may improve patient outcomes, it will be associated with an increased requirement for patients to travel to appointments and careful geographic consideration of location of centres is required to mitigate the burden for families. Current wide variation in service provision and glycaemic outcomes must be addressed to improve care of children with type 1 diabetes in the Republic of Ireland.

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