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

Abstract:
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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 clinical mean haemoglobin A1c ranged from 8.2 to 9.4% (66.1 to 78.2 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. The provision of care for this population requires multidisciplinary input, with the ultimate aim of improving quality of life and reducing long-term diabetes related complications. Improved glycaemic control is the most important way of reducing the risk of microvascular complications. Poor diabetes control is an important modifiable driver of costs associated with type 1 diabetes care. 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.

International Recommendations suggest a caseload per diabetes nurse specialist of between 70 and 100 patients and attendance of a dietitian at diabetes clinic is also recommended. 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 and has improved dietetic access. The National Health Service 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. The provision of care for this population requires multidisciplinary input, with the ultimate aim of improving quality of life and reducing long-term diabetes related complications. Improved glycaemic control is the most important way of reducing the risk of microvascular complications. Poor diabetes control is an important modifiable driver of costs associated with type 1 diabetes care. 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.

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, 8 to 41 in 2011 and 5 to 49 in 2012.

Outcomes

15 centres provided self-reported mean HbA1c, and 14 provided these stratified in age categories 0-9.99 years (7.4 to 8.3), 10-15.99 years (8.1 to 9.9), 16-17.99 years (8.2 to 10.2, 6.1 to 88 mmol/mol) and >18 years (7.2 to 10.4, 55 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% and 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

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 specialist. However, 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 with a nearby centre for this. The number of patients using insulin pumps varied between centres, ranging from 0 to 42% (Figure 3).

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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 appointments were cited as the reasons. 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%), peripartem 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 on pump therapy was varied between 4 and 18 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 care was varied between 16 (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, the availability of multidisciplinary teams in patient numbers, team resources, initiation of insulin pump therapy, clinical guidelines, availability, age of transition and HbA1c levels. 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 specialist care, provided by a team with appropriate expertise.

Diabetes ketoacidosis is present in approximately one quarter of children at diagnosis, which can rarely be avoided and requires immediate treatment. It is characterised by nausea, vomiting, hyperglycaemia and ketonuria, and if not treated, can lead to life-threatening complications such as severe hyperglycaemia, seizures, coma, and death. Effective management of diabetes ketoacidosis is crucial and requires prompt diagnosis, rapid administration of insulin and fluid replacement. This is a major challenge for healthcare providers, especially in small centres with limited resources. In this study, 14% of centres reported difficulties in managing diabetes ketoacidosis, highlighting the need for ongoing training and education to improve clinical outcomes.

Severe hypoglycaemia can occur in up to 40% of patients, and can be associated with seizures or coma. Fear of hypoglycaemia can lead to significant impact on parental quality of life and may have a negative impact on glycaemic control. Data on these factors were not collected in this audit. Other cardiovascular factors such as blood pressure and lipids are also likely to affect outcome.

While this study will inform future paediatric diabetes care in Ireland, the data has a number of limitations. All centres are self-reported, and required providers to manually find and input data. Accuracy is challenging in this context and may be influenced by factors such as median, and percentages of patients achieving targets was not possible. Shared care of patients between centres is not stratified 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 benchmarking 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 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. However, this variation in structure and process of care, and the impact on glycaemic outcomes must be addressed to improve care of children with type 1 diabetes in the Republic of Ireland.


