

Development of a paediatric diabetes education programme

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ARTICLE POINTS

1 The education programme is structured to provide a designed and auditable diabetes education system for children.

2 Points to consider when setting up a new clinic and auditing patient satisfaction are examined.

3 An age-banded annual review of education and shared management of care is included in the education programme.

4 The education package has received positive evaluation by families.

KEY WORDS

- Education
- Newly diagnosed
- Shared management of diabetes

Introduction

The rising numbers of children diagnosed with diabetes and the increasing use of intensive treatment regimens presents the challenge to diabetes care teams of how to most effectively deliver the necessary education. As a response to this challenge the diabetes care team at The Royal Hospital for Sick Children in Edinburgh considered new approaches. In this article the efficacy and acceptability of a new patient education clinic, annual education checks and consideration of the shared management of the condition between child and parent(s) are explored.

In Standard Three of their document for diabetes, the Clinical Standards Board for Scotland state that 'All people with diabetes have equitable access to information and multidisciplinary programmes of education, which are tailored to individual needs and specific client groups (Clinical Standards Board for Scotland, 2001).

Within the previous system of patient education at the author's hospital, after an initial short admission to hospital, children newly diagnosed with diabetes were followed up at home, where they would receive the majority of their ongoing education. Depending on their progress, they would be seen regularly at the review clinic. Problems highlighted by the diabetes team with this system of education were as follows.

- Early discharge with intensive support from diabetes specialist nurses (DSNs) was well received but very time consuming to deliver.
- As the dietitian was unable to make home visits, the young people with diabetes had to visit him/her at the hospital; therefore, this was time consuming for the child and his/her parent(s).
- Young people newly diagnosed with diabetes were being seen at the review clinic and it was becoming impossible for them to receive sufficient input, particularly from the dietitian.
- Due to the large numbers of children

attending the review clinic at one time, it often ran late, particularly if there were a lot of children attending for their annual review visit.

- Existing patients were unable to be seen by the dietitian due to time constraints.
- There was no formal or audited evaluation of the patients' knowledge.

As is often said 'If you want something done well, do it yourself' – for a person with diabetes this requires a thorough understanding of the condition and its management. In order to provide a structured and evaluated education programme for children with diabetes and their families at diagnosis, integrated care pathways for initial clinical management and education were already in place. A pathway for those diagnosed in diabetic ketoacidosis and going to the high dependency unit, and a pathway for the comparatively well child going to the ward were in use. The pathways were devised by the diabetes team, in discussion with the ward staff, to standardise care depending on the initial presentation.

In addition to this, patients and their families were given a copy of *Your Diabetes Handbook* (Royal Hospital for Sick Children Diabetes Team, 2004). Ninety-eight per cent of families who responded to a survey expressed their satisfaction with the handbook.

After much discussion, the diabetes team agreed that a clinic provided purely for newly diagnosed patients would be a

possible solution to some of the problems associated with providing education at initial diagnosis.

A new patient education clinic

Having a separate clinic for newly diagnosed children was thought to be beneficial, particularly in terms of provision of dietetic education to the new patients and in freeing up more time for existing patients at the review clinics. A number of points had to be considered before embarking on this new system:

- timing – clinic room availability, staff availability and length of consultations
- format – who the family sees and when, what is taught and by whom
- personnel availability – dietitian, nurse, doctor and clerical staff
- documentation – structure of what is taught and at what stage of the education curriculum
- frequency of appointments.

The new patient education clinic was set up in January 2003, and is currently held on a Monday afternoon in the outpatient department. Families are given a letter before discharge from the ward outlining the education plan and indicating what to expect from the clinic while pointing out that the plan will be adapted for individual children and their families. If, for example, the family are going on holiday the following week, then how to plan for and manage this is going to be on top of their agenda rather than how to cope with, for example, school issues. Patients attend for four half-hour visits with the DSN and the senior dietitian at weeks 1, 3, 6, and 9. At week 12 they attend an hour-long appointment with a doctor from the diabetes team for an overview and an evaluation of their diabetes knowledge and treatment.

A few patients had difficulties in attending the clinic, mainly due to their location and lack of transport.

All members of the team, including the outpatient nurse, use the same specially devised documentation (the Diabetes Education Plan for the New Patient Clinic), which includes the following.

- Date of diagnosis.
- Patient weight and insulin doses on the

day of the clinic visit and any proposed changes.

- Review of: basic care; whether parents are aware that they are eligible for a disability living allowance, and how to apply for it; school/nursery issues (for example, whether schools know how to deal with a hypoglycaemic episode and any considerations for school trips); hypoglycaemic episodes; insulin dose adjustments to deal with particular activities, such as parties; holidays; sick day management; ketones; injection technique and meter care review. These reviews are carried out by the DSN.
- Review of: basic nutrition; sport/exercise; knowledge of food labelling; glycaemic index. These reviews are carried out by the dietitian.
- Review and assessment of knowledge of diabetes, discussion of HbA_{1c} and annual review. This review is carried out by a senior member of the medical team.
- Results of blood tests for free thyroxine, thyroid stimulating hormone, anti-peroxidase antibodies and anti-transglutaminase antibodies.
- Space for comments and signatures of staff involved at each visit.

The Diabetes Education Plan for the New Patient Clinic document remains in the child's medical notes at all times. A template letter (containing information regarding the education provided, the progress of the child's diabetes and the care he/she is being provided with) is used by staff for each visit and is sent to the child's GP, with a copy to the child's medical and nursing case notes. The information is also recorded by the relevant member of staff onto the hospital's database system.

The result of the HbA_{1c} taken at the final clinic visit (at week 12) to the new patient clinic is available 2 days later. On that day the DSN contacts the parent(s) with the result and arranges a time and date for a home visit, at which the DSN carries out an assessment of understanding and educational needs using a 12-question tool. This includes discussion on hypoglycaemic episodes, HbA_{1c} levels, ketones, exercise, injection sites and basic insulin adjusting. Auditing

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2 The annual review clinic was seen as an opportunity to consider the shared management of the diabetes between the parent(s) and the child.

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of the families' knowledge at the home visit has been positive, but sometimes the understanding of the presence of ketones in the urine and its significance is not fully understood, so this would need to be discussed again. The patient is then seen 6 weeks later (at week 18) at the review clinic.

Telephone contact is encouraged between clinic visits. Home visits continue to be provided when necessary and, as under the previous system, the child's school receives a visit when he/she is newly diagnosed. In addition to these visits the hospital diabetes centre run annual information sessions for school staff at the end of the summer term and the beginning of the autumn term. These sessions include a presentation, a practical session, an interactive session and an opportunity to discuss individual cases confidentially. The sessions cover an overview of diabetes in children and young people: exercise management; treatment of hypoglycaemic episodes; blood glucose testing; insulin injections; and any considerations to be made for school trips. Evaluation of the sessions, assessed by a short questionnaire handed out and completed at the end of each session, has been very positive.

Patient/family evaluation

Patient and family satisfaction with education at diagnosis and with the new patient education clinic has been evaluated by means of two short surveys. These asked about the amount and content of the verbal and written education provided. There was a 42% response rate from the families. This was generally very positive with some useful comments and suggestions, for example:

- the clinic is well structured
- people felt well supported
- handbook should be colour-coded by topic (this was done for the revised edition; Royal Hospital for Sick Children Diabetes Team, 2004).

A recent audit has been carried out looking at the HbA_{1c} levels 1 year post-diagnosis for the year prior to the clinic and the first year of the clinic and the results do not show significant changes.

Having completed the first three months of education for the newly diagnosed child, the team felt that it was important to provide a structure for ongoing assessment, education, and updates.

Ongoing education

The annual review clinic visit was considered an appropriate opportunity to provide ongoing education. It was also seen as an opportunity to consider the shared management of the diabetes between the parent(s) and the child. The assessment of educational needs at the annual review was introduced in June 2004.

Effective parental support of a child with diabetes requires the parent(s) to be focused and anticipatory if their child is to develop appropriate self-management skills. Provision of a pragmatic and developmental structure is important as the management gradually transfers from parent(s) to child. At difficult times (for example when the child is unwell or sitting exams) the parent(s) may need to reassume management of some of the necessary tasks and provide increased support for the child (Kieckhefer and Trahms, 2000).

The annual review session consists of three 20-minute sessions with the DSN, the dietitian and the doctor. The education session with the DSN assesses the practical aspects of injecting insulin, self-monitoring of blood glucose and care of equipment, as well as management of hypoglycaemic episodes, sick day management and exercise management.

In addition, the session also assesses the stage of self-management the children have reached and whether they are receiving appropriate support, for their age and developmental stage, to enable them to become more independent in their self-management. This has proved very enlightening, not only for the DSNs, but also for the parents, as many children have a much deeper knowledge than is realised. This acts as a reminder to us all that knowing what to do and doing it are not the same thing; knowledge is not the only criteria for determining how an individual copes with his/her condition (Meetoo and

Gopaul, 2005).

The hospital diabetes centre is involved in an ongoing audit of this scheme. The centre has had a small number of occasions where follow up visits have been needed on certain aspects of education (for example, when a child is unwell, the visit may go over sick day guidelines again). A suggestion, which may be considered, is a joint appointment with a doctor and a DSN, which would require a doctor to be allocated to do annual reviews at a clinic.

Children who have poor glycaemic control or who are suspected of missing insulin injections may be admitted to the ward for review of their glycaemic control. During this time their knowledge is further assessed using multiple choice questions on blood glucose monitoring, insulin management, and travel and exercise management. The children seem to enjoy this and it usually generates plenty of discussion about their diabetes and how they manage unusual situations. They also enjoy using the CD-ROM *All About Diabetes* (Nottingham City Hospital NHS Trust and Lilly Diabetes Care, 1999), which includes educational sections on diabetes and diet, insulin activity, and stress and illness.

Assessing the programme

Assessing the effectiveness of the diabetes education programme involved looking at the following criteria.

- Patient/family satisfaction as assessed by the use of questionnaires with regard to the education at diagnosis and the new patient clinic.
- An assessment of knowledge carried out at the new patient clinic visit number five (week 12) with a doctor, and at the home visit 6 weeks later.
- An assessment of knowledge carried out at the annual review session with the DSN.
- An assessment of knowledge carried out at a further home visit if necessary, with the aid of a multiple choice quiz.

Conclusion

The introduction of the new patient education clinic and structured sessions at the annual review visit has enabled the

diabetes team at the Royal Hospital for Sick Children to provide a consistent, high quality package for the hospital diabetes centre's families, within the resources available. There has been a positive response from many parents who have stated that they found the sessions useful. The centre has not demonstrated a reduction in HbA_{1c} at 1 year post-diagnosis. However, this was not the aim, as the centre's target was to ensure a complete package of ongoing education and assessment of the quality of education provided, whilst looking at the development of the shared management of diabetes between the child and the parent(s). ■

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