

Integrating group education into paediatric diabetes care: FACTS

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Introduction

The Families, Adolescents and Children's Teamwork Study was developed in Ipswich in 2003 in response to the need for a family-centred, skills-based diabetes education programme. The programme aims to improve diabetes self-management by skills training and encouraging parent/young person teamwork, and, therefore, hopefully improve glycaemic control. It consists of four small group sessions: two that are predominantly skills-based (carbohydrate counting and insulin dose adjustment); and two that are based on social learning theory (exploring parental and child responsibilities, and communication issues). The programme is fully integrated into routine clinical care, with each session taking place on the same day as the regular quarterly outpatient visit.

Good glycaemic control is vital to the long-term health and well-being of children living with diabetes (Diabetes Control and Complications Trial Research Group, 1994). However, the process of achieving and maintaining this is fraught with difficulties (Mortensen et al, 1998).

It has been highlighted that chronic disease management is hindered by a lack of knowledge and low self-efficacy on the part of the patient, and poor role modelling and uninformed help from family members (Glasgow et al, 1999). Consequently the importance of family support in the areas of communication, problem solving of tasks related to daily diabetes care and knowledge of disease management were viewed as crucial elements for inclusion in an education programme.

For an intervention to be effective in terms of cost and impact, it must be implemented and embedded in service provision, and attempt to maximise empowerment through self-care (Barlow and Ellard, 2004). So the Families, Adolescents and Children's Teamwork Study (FACTS) was developed in partnership with parents who advised on the content, location and timing of the sessions. It aims to engage both parents and children, with an emphasis on teamwork and improved

communication, thereby promoting increased sharing of the complicated tasks involved in a child's daily diabetes management routine. The small group setting facilitates increased contact with other children/families, which helps foster a greater sense of peer identity for the children. A major emphasis of the programme is the benefit of increasing flexibility in relation to both eating habits and insulin injections. It also acknowledges the demands of busy family life by coinciding with routine clinical appointments, as suggested by parents during the consultation phase. Therefore, time traditionally spent in the waiting room is used more effectively and helps attract those who may not otherwise attend for additional educational activities.

Programme development

The content of FACTS was developed following careful consideration of existing paediatric and adult education programmes. The curriculum was finally based on educational materials, developed by Barbara Anderson and colleagues in Boston for delivery to individual families by trained nurses (Anderson et al, 1999; Laffel et al, 2003). With the assistance of local parents this material has been adapted to provide appropriate information on carbohydrate counting, insulin

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1 The Families, Adolescents and Children's Teamwork Study (FACTS) was developed in partnership with local families.

2 Family support in the areas of problem solving, communication and knowledge of diabetes self-management are crucial elements of the FACTS.

3 Healthcare professionals involved in the programme delivery have all received expert training by an experienced health psychologist.

4 Early data suggest a beneficial effect on both family responsibility and glycaemic control.

KEY WORDS

- Carbohydrate counting
- Insulin dose adjustment
- Skills-based
- Communication
- Education

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1 Adult studies of diabetes education suggest that the way in which education and information are presented and perceived is of great importance to the internalisation of education.

2 Foods that are eaten commonly by the children are used as examples to highlight the effect on glycaemic control and calorie intake.

3 The families'/children's existing knowledge of insulin dose adjustment, blood sugar testing and HbA_{1c} was established and built upon.

regimens and dose adjustment. The adaptations also facilitate delivery by multidisciplinary team members in a small group setting.

Adult studies of diabetes education suggest that the way in which education and information are presented and perceived is of great importance to the internalisation of education and thus this material has been designed to be colourful and attractive to younger people (Knowles, 1990). All families receive a copy of these materials at the end of each session. This allows topics to be discussed with other family members and provides reinforcement of the information already received before new topics are introduced.

Summary of programme content

Session 1: Food enjoyment with carbohydrate counting

Carbohydrate counting is presented as a useful tool for improving knowledge and understanding of the effects of different foods on blood glucose. Foods that are eaten commonly by the children are used as examples to highlight the effect on glycaemic control and calorie intake. Literature demonstrates that there are very few descriptions of carbohydrate counting for children and families (Waldron et al, 2002). The content of this session is outlined below.

- An introduction to establish what carbohydrate counting is and how it may be useful is given.
- Sources of carbohydrates are identified and categorised as sugars or starches.
- Practical examples, of what each child has eaten for breakfast that morning, are used to identify the carbohydrates and how these may be counted by using food labels, weighing or using handy measures. Food reference tables are introduced and used as required.
- Snacks – children choose their favourite snacks from a variety of healthy and sweeter options and work out which ones are suitable. The use of snacks before sports and to treat/prevent hypoglycaemic episodes is discussed.
- Family meals – the carbohydrate content of 100g dry basmati rice is calculated and compared to the cooked portion to

demonstrate the difference that cooking makes to the carbohydrate value. Families work together to read the labels, weigh their portion and work out the carbohydrate content of their own portion size.

- Follow-up – those who wish to practise carbohydrate counting at home are given food diaries, books and scales and are asked to calculate their average daily carbohydrate intake.

Computer analysis of food diaries completed following the session revealed that this simple practical session resulted in effective estimation of carbohydrate content with minimal differences between computer and parent/young person estimates. This suggests that carbohydrate counting can be effectively taught in small groups using real life examples and practical interactive activities. The session appears effective in providing accurate dietary knowledge; however, it is too early to determine if improvements in insulin dose adjustment and lasting behavioural change will follow.

Session 2: Insulin dose adjustment, blood sugar testing and HbA_{1c}

In this session the families'/children's existing knowledge of insulin dose adjustment, blood sugar testing and HbA_{1c} was established and built upon. The paediatric clinic at Ipswich Diabetes Centre uses a variety of insulins and regimens to suit individual needs. Consequently the group discussions provided diverse information and a good learning opportunity for all concerned. The session content is outlined below.

- An introduction and a brief review of the group's experiences with carbohydrate counting, with all efforts praised, is followed by an outline of the current session contents.
- Exploring attitudes to blood glucose testing – the use of a card game explores the facts and fictions of blood glucose monitoring. The children are encouraged to think about their own blood glucose targets and comment on how easy or difficult these are to achieve. Factors that raise and lower blood glucose are identified, with emphasis placed on the fact that, although food is important, it is not the only factor contributing to out-of-range values.

- Understanding HbA_{1c} – parents and children are asked what their HbA_{1c} value was at the day's clinic visit and what this means to them. A practical demonstration follows where children pour sugar onto 'red blood cells' (made from play-dough), this represents glycosylation of haemoglobin.
- Basic facts about insulin and injection technique are discussed with the help of a card game with names of different insulins and their peak action times to be matched together. Insulin absorption from different sites and site rotation are also discussed.
- The session concludes with examples from monitoring diaries used to adjust insulin doses – children identify a pattern of high blood sugars, discuss likely causes and suggest a range of solutions. Each child/young person decides which solution they prefer. Regular review of diaries or blood glucose meter values is recommended at home to encourage parents to elicit their child's opinions and to gain confidence in problem solving as a team.

Session 3: Teamwork and communication to support blood glucose monitoring

Sessions three and four are facilitated rather than taught. An icebreaker exercise elicits the following responses that guide the session and reflect upon life with diabetes:

- teamwork
- getting out of a mess
- rely on someone else to co-operate
- have a laugh
- getting to know people
- how to work out a problem with each other
- trust each other
- there are lots of solutions
- always a way out
- cannot always get it perfect.

Children and parents draw a picture of doing a blood sugar test at home (see Figure 1 for an example). The families are asked to describe what is happening in the pictures that they have drawn. A second picture of what happens when their blood sugar is higher than 22mmol/L is then drawn (see Figure 2 for an example). The discussion that follows focuses on how families react to blood glucose values that are out of range.

Session 4: Interdependence, sharing responsibility and letting go

Once again, little input is required from the group facilitator as families share and reflect upon their own experiences. The facilitator instructs the following.

- Draw a train representing your diabetes team.
- Who is driving it and in which carriage do you sit?
- Are you happy with where you are?
- How can you see this changing?

(See Figure 3 for examples of drawings based on these leading questions.)

Implementation

The programme is designed for delivery by different members of the multidisciplinary team, which helps to avoid educator fatigue. The sessions are run from 11am–12pm, toward the end of a busy morning clinic, which gives several team members a chance to be involved. Appointments for those attending the groups are scheduled for prior to 11 am and every effort is made for the clinic review to take place on time. A dietitian delivers the first session. A paediatric nurse specialist or doctor delivers the second session. A nurse trained in counselling techniques facilitates the third and fourth, family-based, sessions. The aim is for age-banded sessions for children (11 years or less) and young people (12–16 years), with each group consisting of three or four families. However, due to frequent cancellation of appointments by the families, due to other commitments, the sessions do not always run according to this plan.



Figure 1. Drawing from a third session. The facilitator instruction was 'draw a blood sugar test being done in your home.' Large hands and sad faces were a common feature of these drawings.

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3 Early data suggest beneficial effects on glycaemic control, particularly in those who have incorporated more frequent correction boluses in addition to their usual insulin requirements.

4 It is interesting to note that those who changed to a more intensive insulin regimen without taking part in the programme had no improvement in HbA_{1c}.



Figure 2. Example of a drawing from the third session. Facilitator instruction was ‘draw what happens in your home when your blood sugar is higher than 22.’ This drawing illustrates a pragmatic response, though a sad face is still apparent.

A key feature of this programme is that each healthcare professional has received training in the delivery of group education from an experienced health psychologist. Although daunting at first, this exercise was found, by the staff involved, to be beneficial for daily practice as well as for group education delivery. It has also enabled the programme to be delivered by local staff while making effective use of the limited health psychologist resources available in the UK.

Results

The preliminary data from a randomised controlled study on FACTS are promising. Sixty-seven adolescents (51% female, mean age 11.3 years) were randomised to attend (n=33) or not to attend (n=34) the FACTS programme (those not attending the FACTS sessions initially will join the educational programme after the first year of the study).

Use of the Diabetes Family Responsibility Questionnaire (Anderson et al, 1990) showed a lack of agreement between parents and children regarding responsibility for diabetes self-management tasks. This improved in those that attended the FACTS sessions, whereas an increased discrepancy was found in those that did not attend (Figure 4). Those who completed the programme also demonstrated more adolescent and parental involvement in care and improved glycaemic control. More people attending the programme requested a change to intensive insulin regimens than in the non-attending group ($\chi^2=7.57$; degrees of freedom = 1; $P < 0.05$), though there were no differences on total daily insulin doses between groups. Early data suggest beneficial effects on glycaemic control, particularly in those who have incorporated more frequent correction boluses in addition to their usual insulin requirements. It is interesting to note that those who changed to a more intensive insulin regimen without taking part in the programme had no improvement in HbA_{1c}.

Evaluation of the programme by the users

Feedback was provided by the families upon completion of the course. Eighty-nine per cent found the carbohydrate counting useful and interesting, particularly the group discussion, written information (food reference tables) and practical demonstrations. A similar percentage (90%) rated the second session useful, particularly in providing information about alternative insulin regimens and the importance of using blood glucose values to adjust insulin doses. Feedback on the teamwork and communication session highlighted the importance of honesty, working together as a team and realising that there are others in the same situation. The final session was also favourably received, with comments indicating that the participants feel better supported when things are shared, that blaming is not useful and that ‘mum will feel much better if I help out more.’

Two comments were received from participants highlighting discomfort with the psychological angle of the third and fourth sessions. One comment was:

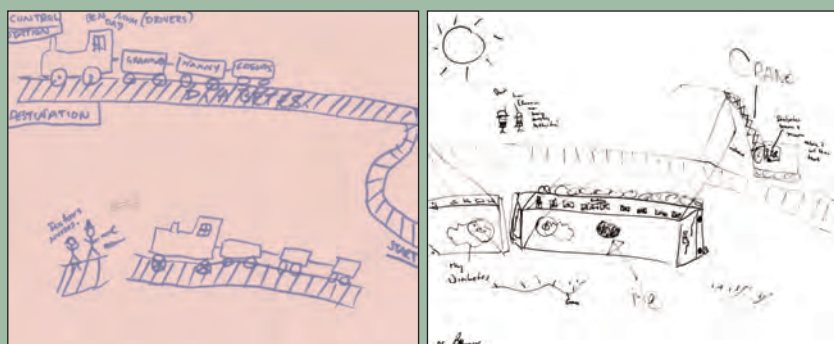


Figure 3. Examples of drawings from the fourth session. The facilitator instruction was ‘draw a picture of a train that represents your diabetes team.’ Left: The child and parents are drivers of the train, with extended family and friends in the carriages. The diabetes team are at the side with tools to hand. Right: The diabetes team and family are in the crane attempting to right the derailed train with the child in it. Other family members observe at a distance.

'Not sure about this session – I felt it was too geared towards psychology [with] deep hidden meanings in everything. However, I felt it very useful to remind all the family diabetes care is better shared and supported.'

Overall, most families found the subjects covered very useful and stated that they learnt a great deal. Several distinct messages could be identified in the participants' evaluations:

- group work/discussion was liked enormously
- talking to other people with the same problems was very useful
- written information was valued
- practical sessions were highly rated.

The demands for the future included:

- further opportunity to meet and work in groups incorporating different topics
- provision of written materials to support learning
- further opportunity to discuss individual insulin regimens and lifestyles
- whole family involvement (most children were only accompanied by their mother).

Implications

This is the first randomised trial of a family-based structured education programme in the UK. Its strengths are that it was developed in partnership with parents and based on scientific evidence that parental involvement is the most important predictor of positive adolescent outcomes (Anderson, 2001). It is clearly described and guided by a firm educational theory (Huws-Thomas et al, 2005). This allows others to review the key elements and make further modifications. The supervision of sessions by a health psychologist has not only improved the performance of these groups but also increased the satisfaction of the educators. While the integration into routine care is not always as smooth as the investigators would hope for, families have been very understanding when sessions have had to be postponed due to insufficient numbers or clinical emergencies.

Ipswich Hospital Diabetes Centre is currently planning the extension of the programme to newly diagnosed families, and working out ways of providing ongoing support for those who have completed the course. ■

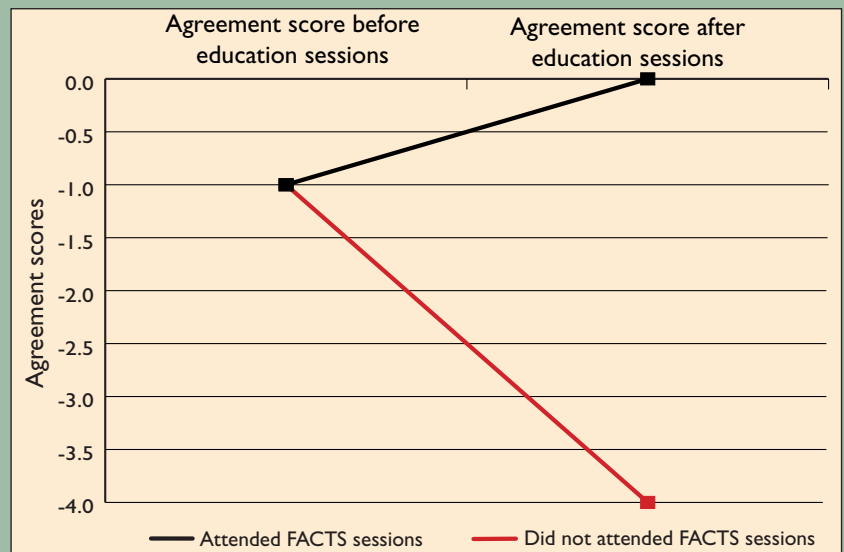


Figure 4. Agreement between parents and children on responsibility for diabetes management tasks. Baseline scores show disagreement between parents and young people about who is responsible for certain self-care tasks; this is reduced in those who attended the education programme and increased in those who did not.

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