

A health education group intervention for children with type 1 diabetes

Clarissa Martin, Katie Liveley,
Karen Whitehead

Article points

1. Structured health education programmes should be offered to children and young people with diabetes.
2. Health education programmes using creative, interactive techniques are effective for children with chronic conditions.
3. This study highlights a discrepancy between the perceptions of children and their parents in relation to diabetes management.

Key words

- Diabetes management
- Coping
- Health education

Clarissa Martin is a Consultant Paediatric Clinical Psychologist, and Katie Liveley is an Assistant Psychologist, South Staffordshire and Shropshire NHS Foundation Trust. Karen Whitehead is a Paediatric Diabetes Nurse Specialist, Mid Staffordshire NHS Foundation Trust.

Type 1 diabetes is a common chronic condition in children and young people and its incidence has doubled in the last two decades. This article aims to highlight the benefits for children with type 1 diabetes of health education interventions that utilise psychological approaches. It details the authors' group-work techniques and presents an evaluation of their pilot study. The aim of the pilot study was to explore the effectiveness of a health education intervention for a group of children with type 1 diabetes.

Type 1 diabetes is the third most common chronic condition in children and young people (Betts et al, 1996), and its incidence has doubled in the last two decades (Hampson et al, 2001). The DCCT (Diabetes Control and Complications Trial) Research Group (1994) and the *National Service Framework for Diabetes* (Department of Health, 2001) have established the importance of good diabetes control in reducing diabetes-associated health problems. As people with diabetes are usually responsible for the everyday management of the condition, a knowledge of diabetes and the practical skills needed to deal with it are of great importance, and both can be gained through patient education (Johnson et al, 1982).

Following the results of the DCCT, Brink and Moltz (1997) recommended that people with diabetes undergo a diabetes education plan with continuing assessment and re-education. Various guidelines (International Society for Pediatric and Adolescent Diabetes [ISPAD], 2000; NICE, 2004) highlight education as the cornerstone of diabetes management, suggesting that it should

be a lifelong process and that children and young people with diabetes should be provided with information and a structured programme of diabetes-related education.

Reviews of the literature focused on diabetes education programmes developed for children and young people have highlighted that educational interventions are useful for improving diabetes knowledge, but are not consistently helpful in improving metabolic control (Grey, 2000; Murphy et al, 2006). It is assumed that improving knowledge and skills leads to better adherence and metabolic control, but some studies indicate that this is not the case (Bloomgarden et al, 1987). Although knowledge is the minimum requirement necessary for appropriate self-management, it is not sufficient for achieving good adherence (Johnson, 1984; Wysocki et al, 1992). The interaction between adherence and blood glucose levels is quite complex, and it is impacted by several interrelated factors (such as regimen, insulin resistance, and residual beta-cell activity; Delamater, 2000).

Various studies have demonstrated the benefits

of programmes that provide a more creative approach to adherence. FACTS (the Families, Adolescents and Children's Team Work Study) is a family centred, structured education programme for children and adolescents with type 1 diabetes, which demonstrates the potential benefits of parental involvement in their child's diabetes control (Murphy et al, 2007). Brown et al (1997) evaluated an interactive video game designed to improve self-care among children and adolescents with diabetes. They found that the game improved diabetes-related self-efficacy and self-care behaviours. In another study, children who attended a therapeutic summer camp with an emphasis on diabetes education also demonstrated improved adherence to self-injection and blood glucose monitoring (Holden et al, 1991). Pélícan and et al (2006) evaluated a therapeutic education program that used puppets as a means to enable children with diabetes to express their difficulties with the condition. The authors of that study found that providing creative approaches when delivering health education for children with diabetes were effective for them to express their emotions.

Researchers in other healthcare areas have also demonstrated that children can progress at an advanced rate when learning through games, rather than when they are presented with information in a more formal manner (Makuch et al, 2001). Indeed, Johnson (1984) highlighted that one of the barriers to adherence with self-management techniques may be an inability to understand the oral instructions and reading materials provided by physicians. Simply providing information does not guarantee that children have taken it in, as they may appear knowledgeable even when they are not. For example, after an explanation about diabetes the healthcare professional can ask a child if he or she has understood, the child can answer yes but the non-verbal language may be giving signals that he or she has not grasped the concept. The healthcare professional can also explain again and perhaps the child would be able to repeat some of the sentences mainly because he or she is using short-term memory processes. Furthermore, particular care should be given to how professionals communicate and provide information to children and young people with diabetes (NICE, 2004). Recent research demonstrates that group work interventions using cognitive and behavioural approaches were effective in children with diverse

illnesses, with improvements demonstrated in knowledge of illness, coping skills and symptoms (Last et al, 2007).

Education is considered to be an essential part of the care package for children and young people with diabetes, and information has to be explained in such a way that it can be understood. The method of delivering education and content should be appropriate for the age and level of development of the child or young person (ISPAD, 2000; NICE, 2004). The aim of the pilot study below was to explore the effectiveness of a health education intervention delivered to a group of children presenting with type 1 diabetes.

Methods

Participants

Five children who had been newly referred to a paediatric psychology service because of their difficulties with diabetes management, and who also had associated behavioural problems, were invited to join a Diabetes Group. Three of the children, one girl and two boys, subsequently accepted and joined the group. The other two children were from the same family and forgot to come to the first meeting; the parents subsequently declined to participate. They were all aged between 9 and 11 years old.

Measures

The availability of standardised measures for assessing children's knowledge and psychosocial functioning in diabetes is limited – therefore, the authors used non-standardised experimental questionnaires in a pre- and post-intervention design.

Two questionnaires ("Living with Diabetes" and "Diabetes Knowledge") were distributed to the children. Parents completed only one questionnaire ("Living with Diabetes") Questionnaires were provided on the first day of the intervention, before the group session started, and on the last day of the intervention. The "Living with Diabetes" questionnaire was adapted from one facilitated and developed by Caroline Browne (Clinical Psychologist, Manchester), which is still in the experimental phase. The questionnaire was based on nine topics (see *Box 1*) for the children and adults to classify using a 0–10 Likert scale from "extremely easy" (0) to "extremely difficult"(10).

The "Diabetes Knowledge" questionnaire was developed by the paediatric diabetes nurse

Box 1. The topics comprising the "Living with Diabetes" questionnaire.

1. Looking after diabetes.
2. Coping with feelings.
3. Coping with being different.
4. Ease of talking to friends.
5. Ease of talking to family.
6. Ease of talking to healthcare professionals.
7. Social life.
8. Management at school.
9. Feelings about the future.

Box 2. The questions comprising the "Diabetes Knowledge" questionnaire.

- What is diabetes?
- Where do you give your injection of insulin?
- When do you give your injection of insulin?
- Besides insulin what else is important to keep well?
- What makes blood sugar levels go up and down?
- What do you do if you have a hypo?

Page points

1. There were three group sessions, where new means of learning about diabetes were explored using experiential and cognitive techniques that included to look at how children made sense of the diabetes (cognitive processes) and why they thought diabetes had happened to them (cognitive attributions).
2. A paediatric diabetes nurse specialist and an assistant psychologist ran the groups under the supervision of a consultant paediatric clinical psychologist.
3. The children listened to an educational story about diabetes, which focused on helping them understand the condition as well as reinforcing that having diabetes was not their fault.

specialist, and involved interviewing the children separately to examine their understanding and knowledge of diabetes. This questionnaire consisted of six open-ended questions relating to the management of diabetes (*Box 2*).

Sessions

There were three group sessions, where new means of learning about diabetes were explored using experiential and cognitive techniques that included examining how children made sense of their diabetes (cognitive processes) and why they thought diabetes had happened to them (cognitive attributions). A paediatric diabetes nurse specialist and an assistant psychologist ran the groups under the supervision of a consultant paediatric clinical psychologist.

The first session introduced and explained the group work rationale to the children in a child-friendly style. After completing the questionnaires, the children listened to an educational story about diabetes, which focused on helping them understand the condition as well as reinforcing that having diabetes was not their fault (Pesterfield, 2005).

In the second session, the children listened to another educational story which uses metaphor and relaxation to help them to think about diabetes in more positive terms and promotes self-esteem (Thompson, 2005). The story served a further purpose as a cautionary tale aimed to encourage children to follow medical advice and their diabetes treatment. Group discussion was

facilitated, and the children drew pictures relating to the story they had listened to.

The third session was a one-to-one intervention aimed at improving the children's diabetes knowledge using an interactive computer software package (Showme Multimedia Ltd and Nottingham City Hospital NHS Trust, 1999). The application uses entertaining games to help children learn about diabetes management, exercise and healthy eating. For example, one of the interactive computer games was based on raising awareness of hypoglycaemia: 12 cards are shown and the game asks the child to identify the food or drinks that would be suitable for treating an episode of hypoglycaemia by clicking on the six correct cards, different sounds are made for getting it right or wrong. Another game involves flying a plane and keeping it airborne by taking on extra fuel to prevent the plane from crashing; the message for this is that if the child does not take extra fuel (food) at regular intervals then he or she could have an episode of hypoglycaemia.

Results

Questionnaires completed by the children and the parents before and after the health education intervention were studied and analysed. The evaluation not only explored the overall effectiveness of the group intervention but also allowed the authors to look at the results of the individual cases. Therefore, a summary of the quantitative global results of the group findings are presented, followed by individual results discussed from a case-study perspective, which included psychological formulation of the child's presenting problem at the time of the intervention, that is, a description of the problem in terms of the factors involved. In general, psychological formulations aim to facilitate the psychological intervention through modifying those factors. We have included this point of view with the aim of developing a "whole child" approach when describing the results of this intervention.

Combining the children's and adults' scores from the "Living with Diabetes" questionnaire suggest that the interventions had a positive general effect. Overall results showed that the children's perceived level of difficulty in living with diabetes decreased after the intervention. However, although the parents' perceived level of difficulty that their children were experiencing in dealing with diabetes also decreased after the group intervention, parents' scores were

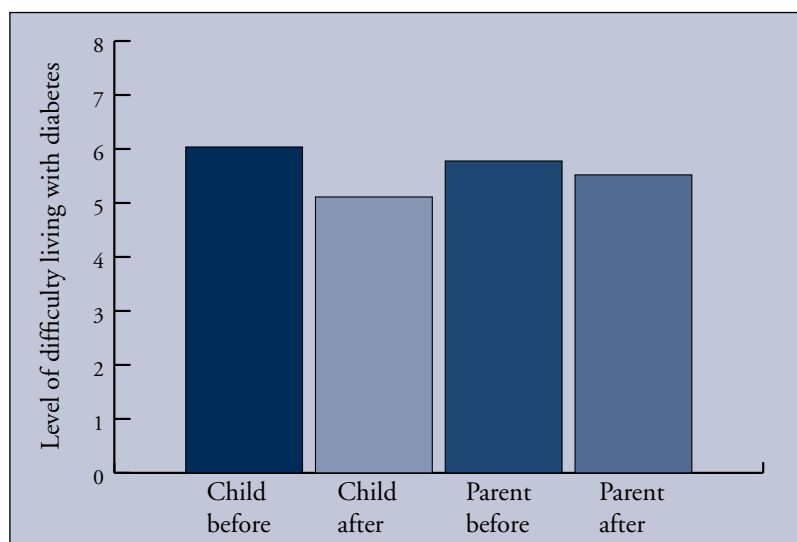


Figure 1. Mean scores obtained on the "Living with Diabetes" questionnaire as a measure of the overall effect of the intervention.

higher than those obtained by their children (Figure 1). The data collected from the “Diabetes Knowledge” questionnaire are not shown due to space restrictions, however they can be obtained from the author if necessary.

Case study 1

Child A is a 9-year-old boy who was diagnosed with diabetes at 6 years old, and has now presented with behavioural problems. As a first formulation it was suggested that child A’s diabetes could have predisposed him to behavioural problems, which may have been precipitated by parental separation. The child’s behaviour was maintained by a lack of understanding of the diabetes regimen and inconsistent behavioural management. However, the child’s high confidence and relationship with his sister were protective factors.

Child A demonstrated the highest overall improvement in perceived level of difficulties in dealing with diabetes in comparison with the rest of the participants. Before the interventions, Child A gave five of the nine indicators the highest

possible rating of “extremely difficult” – after the interventions, he reported a decrease in difficulty in living with diabetes (Table 1). However, he still experienced difficulties in talking to healthcare professionals. Overall, Child A’s parents perceived his difficulties as being greater than he did, however, the parent’s scores did indicate that the intervention had had a beneficial effect (Table 1).

Case study 2

Child B is a boy of 11 years who had been diagnosed with diabetes at the age of 6 and also has asthma and mild learning difficulties, which were possible predisposing factors for his behavioural problems. The child’s unsettled family situation also acted as a precipitating factor for his difficult behaviour. It was also felt that a lack of understanding about diabetes might be exacerbating child B’s behavioural problems. The protective factor in this case appeared to be the dynamic relationship between the child and his primary caregiver.

The intervention decreased the level of

Table 1. Scores from the “Living with Diabetes” questionnaire for each question asked of the parents and children (see Box 1 for topics).

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Overall	Mean
Case 1											
CB	6	10	0	10	7	0	10	10	10	63	7.00
CA	2	6	4	2	1	1	6	3	8	33	3.67
PB	9	9	8	8	8	7	8	9	9	75	8.33
PA	7	10	9	0	3	8	7	9	10	63	7.00
Case 2											
CB	7	8	4	6	9	5	7	3	9	58	6.44
CA	6	5	7	3	3	8	5	5	7	49	5.44
PB	5	5	8	6	6	1	6	5	7	49	5.44
PA	6	6	5	5	4	1	6	6	5	44	4.89
Case 3											
CB	4	6	3	1	5	8	6	5	4	42	4.67
CA	3	6	10	5	5	10	0	7	10	56	6.22
PB	7	8	10	0	0	0	0	2	5	32	3.56
PA	8	8	9	0	0	0	5	5	7	42	4.67

CB: Child before intervention; CA: Child after the intervention;
 PB: Parent/caregiver before intervention; PA: Parent/caregiver after the intervention.

Page points

1. This study aimed to monitor the effectiveness of a group education intervention in children with diabetes.
2. The authors believe that health education interventions delivered in a group format could be cost-effective, as well as acting as a referral filter for more specialised interventions.
3. Exploration of the results demonstrates that some aspects related to perception of diabetes appeared to be improved for one family member but not for the other.

perceived difficulties in dealing with diabetes experienced by child B and his primary caregiver. However, contradictory results were received. For example, child B found that the intervention ameliorated the effect diabetes had on the way he coped with his feelings, whereas the primary caregiver reported that he had more difficulties in coping with feelings (*Table 1*).

Results from the “Diabetes Knowledge” questionnaire showed that child B had acquired further knowledge about diabetes management (data not shown). For example, at initial assessment child B believed that his diabetes was caused by his lungs not working properly, however, post-intervention, he demonstrated that he had learned about his pancreas by identifying it on a picture of the inside of the body. He also was able to identify another injection site as he understood the need for rotation. This had been a problem in the past as he was obsessive about having the injections only in one part of his body.

Case study 3

The final case study features child C, a 9-year-old girl who was diagnosed with diabetes when she was 3 years old, and was genetically predisposed to developing diabetes as it ran in her family. The onset of diabetes appeared to have precipitated behavioural problems, with maintaining factors related to a complex family situation. However, the girl’s high intelligence served as a protective factor.

Child C only attended two of the three sessions due to a family holiday. However, despite this, the family still submitted the questionnaires. The results showed that child C and her parents reported more difficulties with diabetes management after the intervention (*Table 1*). These results might be a symptom of a lack of adherence to her diabetes regimen, given that the second survey was completed in the school holidays. Child C’s lack of routine might have in turn affected the diabetes regimen, thus contributing to poor management. Interestingly, however, child C reported that looking after her diabetes was easier following the group intervention, while the mother’s response indicated that it had become more difficult (see results for question 1, *Table 1*).

Discussion

This study aimed to monitor the effectiveness of a group education intervention in children

with diabetes. Although the results showed an improvement in certain aspects of the children’s perception of the diabetes regimen, and illness related knowledge, the small sample size and the lack of standardised measures for assessing children’s knowledge of diabetes are methodological considerations that prevent a wider generalisation of results.

The authors believe that health education interventions delivered in a group format could be cost-effective, as well as acting as a referral filter for more specialised interventions. The results of this approach have provided the authors with invaluable insights into family dynamics and how to facilitate group-work interventions.

Coping with a chronic condition is stressful for the whole family as well as the child. Researchers have suggested that the family dynamic mediates the effect of children’s adaptation to chronic illness, although this causal relationship is dependent on the parents’ level of coping and their perception of their role (Aujoulat et al, 2006).

Exploration of the results demonstrates that some aspects related to perception of diabetes appeared to be improved for one family member but not for the other (*Table 1*). The general results of this study indicate that after the interventions there was an overall improvement in the level of difficulty of living with diabetes. However, results showed discrepancies in the perception of adjustment between parents and children (*Figure 1*). This health education intervention helped the children involved to improve their knowledge of diabetes from a developmental and age-related perspective. However, it did not include any sessions for parents. Perhaps parents were focused in their expectation, in what they thought the child had to do and to learn, instead of the child’s process of learning.

Reducing parent–child discrepancy in perception and knowledge of diabetes would surely be necessary in order for the children to feel supported by their family, which in turn may act as a buffer for the negative effects of living with a chronic condition. When providing an intervention in children with diabetes it is important to maintain a whole-child approach and consider the family system. The influence of family factors in children’s management and perception of diabetes has been highlighted in the literature (Jacobson et al, 1994; La Greca et al, 1995; Faulkner, 2007; Jaser et al, 2008; Matyka, 2008).

In common with previous research, this study used interactive games and group discussions to engage the children in learning about diabetes. The children reported enjoying the sessions, and their knowledge about diabetes subsequently improved (data not shown).

The results and experiences from the study have also helped the authors to reflect on the future implications of this approach. The authors recommend that at the beginning and end of a group intervention, parents should be invited to discuss the different ways in which they could help their child cope with their diabetes.

Conclusions

The authors suggest that health education interventions in diabetes could easily be facilitated by a paediatric diabetes nurse specialist and a play specialist, with access to psychological services for supervision. This may impact positively on the cost effectiveness of services. However, the authors think that recommending this, or other specific education programmes for children with diabetes, is not appropriate at this stage as the evidence is insufficient. Firstly, the content of educational programmes for children with diabetes would need to be standardised; secondly the majority of the research and studies were conducted in the USA, and so may not be applicable in a UK healthcare setting. In the authors' opinion, further research into the education of children with diabetes involving larger sample sizes, and conducted at a national level, is very necessary. ■

Aujoulat I, Simonelli F, Deccache A (2006) *Patient Education and Counseling* **61**: 23–32

Betts P, Buckley M, Davies R et al (1996) *Diabetes Medicine* **13**: 54–9

Bloomgarden Z, Karmally W, Metzger M et al (1987) *Diabetes Care* **10**: 263–72

Brink SJ, Moltz K (1997) *Diabetes Spectrum* **10**: 259–67

Brown SJ, Lieberman DA, Gemeny BA et al (1997) *Informatics Health and Social Care* **22**: 77–89

Diabetes Control and Complications Trial Research Group (1994) *Journal of Pediatrics* **125**: 177–88

Delamater AM (2000) Critical issues in the assessment of regimen adherence in children with diabetes. In: Drotar D (Ed). *Promoting Adherence to Medical Treatment in Chronic Childhood Illness. Concepts, Methods and Interventions*. Lawrence Erlbaum Associates, New Jersey

Department of Health (2001) *National Service Framework for Diabetes: Standards*. Department of Health, London

Faulkner M (2007) *Journal of Pediatric Nursing* **22**: 59–68

Grey M (2000) *Annual Review Nursing Research* **18**: 149–70

Hampson SE, Skinner TC, Hart J et al (2001) *Health Technology Assessment* **5**: 1–30

Holden EW, Friend M, Gault C, et al (1991) Family functioning and parents coping with chronic childhood illness: relationships with self-competence, illness adjustment, and regimen adherence behaviors in children attending diabetes summer camp. In: Johnson JH, Johnson SB (Eds). *Advances in Child Health Psychology*. University of Florida Press, Gainesville, Florida

ISPAD (2000) *Consensus Guidelines for the Management of Type 1 Diabetes Mellitus in Children and Adolescents*. Medical Forum International, Zeist

Jacobson AM, Hauser ST, Lavori JB et al (1994) *Psychosomatic Medicine* **56**: 401–9

Jaser SS, Whittlemore R, Ambrosino JM et al (2008) *Journal of Pediatric Psychology* **33**: 509–19

Johnson SB, Pollak T, Silverstein JH et al (1982) *Pediatrics* **69**: 708–31

Johnson SB (1984) *Clinical Psychology Review* **4**: 503–24

La Greca AM, Auslander WF, Greco P et al (1995) *Journal of Pediatric Psychology* **20**: 449–76

Last BF, Stam H, Onland-van Nieuwenhuizen A, Grootenhuis MA (2007) *Patient Education and Counseling* **65**: 101–12

Makuch A, Reschke K (2001) *Patient Education and Counseling* **43**: 105–10

Matyka K (2006) *Practical Diabetes International* **22**: 325–6

Murphy HR, Rayman G, Skinner TC (2006) *Diabetic Medicine* **23**: 935–43

Murphy HR, Wadham C, Rayman G, Skinner TC (2007) *Diabetic Medicine* **24**: 1261–68

NICE (2004) *Diagnosis and Management of Type 1 Diabetes in Children and Young People*. NICE, London

Pélicand J, Gagnayre R, Sandrin-Berthon B, Aujoulat I (2006) *Patient Education and Counseling* **60**: 152–63

Pesterfield C (2005) *Diabetes Made Simple: A Kids' Guide to Diabetes*. Novo Nordisk Limited, Crawley

Showme Multimedia Ltd and Nottingham City Hospital NHS Trust (1999) *All About Diabetes [CD-ROM]*. Eli Lilly and Company Limited, UK

Thompson L (2005) *Harry the Hypnotomus*. Crown House Publishing, Carmarthen

Wysocki T, Hough, BS, Ward KM, Green LB (1992) *Developmental and Behavioral Pediatrics* **13**: 194–201