Running a complex educational intervention for adolescents with type 1 diabetes – lessons learnt

David Chaney, Vivien Coates, Mark Shevlin

It is estimated that only 20% of all children and adolescents with type 1 diabetes achieve an HbA_{1c} level of ≤7.5% (≤58 mmol/mol) (Cardwell et al, 2005). These figures highlighted the need for structured diabetes education programmes tailored to the needs of children and adolescents in an effort to improve current clinical outcomes. This article outlines issues that arose during a pragmatic randomised controlled trial to investigate the effectiveness of a structured diabetes education programme for adolescents aged 13–19 years. A total of 159 adolescents were recruited from seven participating hospital sites across Northern Ireland; 79 were allocated to the control group and 80 undertook a structured diabetes education programme consisting of 12 hours' education over 4 weeks. The need to consider numeracy, literacy, participant disruption and involvement of parents is discussed, and recommendations for consideration when developing future adolescent education programmes are made.

Article points

1. To-date, there is no tried and tested structured diabetes education programme for children and adolescents with type 1 diabetes in the UK.
2. The process of developing and testing an education programme tailored to the needs of adolescents highlighted a number of issues to consider for future development of such programmes, including numeracy, literacy, motivation, disruption, family conflict, parent involvement, recruitment and completion of the course.
3. Suggestions for resolving these issues and hence ensuring the success of future diabetes education programmes are made.

Key words

- Adolescent
- Randomised controlled trial
- Structured education
- Type 1 diabetes

Authors' details can be found at the end of this article.

The incidence of type 1 diabetes has doubled in the past two decades from 7.0 to 13.5/100 000 per year (Patterson et al, 2009). This lifelong chronic condition requires those diagnosed, or their parents, to undertake a complex regimen of self-care practices, in order to achieve optimal glycaemic control necessary to stave off the potential acute and long-term complications. The ultimate aim of self-care regimens is to achieve an HbA_{1c} level of <7.5% (<59 mmol/mol; NICE, 2004) while maintaining a good quality of life and avoiding frequent hypoglycaemic episodes.

Glycaemic control in adolescence

Although it is widely accepted that good glycaemic control delays the onset and progression of microvascular complications in people with type 1 diabetes (DCCT [Diabetes Control and Complications Trial] Research Group, 1994), the majority of adolescents do not achieve optimal metabolic control. Multinational studies indicate that only 29% of adolescents with type 1 diabetes achieve an HbA_{1c} level of <8% (<64 mmol/mol), even when assisted by a multidisciplinary team involving an endocrinologist, DSN, dietitian and social worker (Mortensen et al, 1998).

Page points

1. In Northern Ireland, only 20% of all children and adolescents with type 1 diabetes achieve an HbA_{1c} level of ≤7.5% (≤59 mmol/mol).
2. Insulin omission, failure to attend scheduled healthcare appointments, fabrication of blood glucose results, and failure to coordinate insulin and dietary intake are all common in this age group.
3. Despite the proven success of structured education programmes for adults, to-date there is no tried and tested equivalent programme for children or adolescents available in the UK.
4. It is imperative that diabetes education programmes developed for adolescents should be based on the fundamental principles of child learning.

Recent figures show that in Northern Ireland, only 20% of all children and adolescents with type 1 diabetes achieve an HbA_{1c} level of ≤7.5% (≤59 mmol/mol; Cardwell et al, 2005). These figures are consistent with those of England and Wales, where the National Diabetes Audit 2008/2009 revealed that only 16.2% of children and young people achieve an HbA_{1c} level of <7.5% (<59 mmol/mol; NHS Information Centre, 2010).

This decline in blood glucose control has been linked with the onset and progression of complications in this young age group (DCCT Research Group, 1994). Although the influence of physiological factors during adolescence is acknowledged in the literature, many have suggested that the deterioration in self-care practices is equally important (Flack et al, 1996) and needs to be addressed in order to improve metabolic control in this population.

Insulin omission (Bryden et al, 1999), failure to attend scheduled healthcare appointments (Skinner et al, 1998), fabrication of blood glucose results, and failure to coordinate insulin and dietary intake (Weissberg-Benchell et al, 1995) are all common practices in adolescents. There is a clear need for a new strategy of care that offers support and guidance to enable adolescents to navigate the daily issues with which they are presented more effectively.

Structured diabetes education

In recent years the need for structured education programmes within paediatric care has been highlighted as a priority both by government bodies and by diabetes organisations (Department of Health [DH], 2003; 2007; NICE, 2003). These programmes are seen as a potential way forward to address the needs of children, adolescents and their parents.

Both DAFNE (Dose Adjustment for Normal Eating) and BERTIE (Bournemouth Type 1 Intensive Education Programme) have been introduced across the UK in an attempt to help adults with type 1 diabetes manage their care effectively. Intensive insulin therapy, problem-solving and skills mastery form large components of these programmes.

These programmes have been shown to be effective in improving metabolic control and quality of life for participants (DAFNE Study Group, 2002). Intensifying insulin therapy alone is not sufficient to improve metabolic control in the majority of people with diabetes (Mortensen et al, 1998); the need to introduce intensified insulin therapy as part of a comprehensive support package in conjunction with diabetes education is well established (NICE, 2004; Swift, 2007).

Despite the proven success of structured education programmes for adults, to-date there is no tried and tested equivalent programme for children or adolescents available in the UK (DH and Diabetes UK, 2005). Given the unique style of learning and level of understanding of this age group, it would be unwise to believe they could simply complete one of the adult-oriented programmes mentioned earlier.

It is imperative that programmes developed for children and adolescents should be based on the fundamental principles of child learning, with particular attention given to recommendations from bodies such as the Office for Standards in Education for teaching children (Kyriacou, 1998). This, together with children and adolescents' views of what they believe they need and want from an education programme, should assist in ensuring that the programmes are successful and of benefit to young people.

Methods

Study design

A registered (ISRCTN13331558) multicentre, pragmatic, randomised controlled trial using pre- and post-intervention measurements to evaluate the efficacy of a structured education programme for adolescents with type 1 diabetes aged between 13 and 19 years was used.

A total of 159 participants were recruited from seven hospital sites over an 18-month period and randomly allocated to either the control (n=79) or intervention (n=80) group. The intervention group participated in a structured diabetes education programme for 3 hours on one evening a week for 4 weeks (*Table 1*), thus completing a total of 12 hours' education.

Table 1. Structure of the diabetes education programme for adolescents with type 1 diabetes tested in the study.

Week	Time	Topic	Facilitator	Unit
1	18.00 – 18.10	Introduction and welcome	DSN/dietitian	
	18.10 – 18.30	Recap on diabetes	DSN	1
	18.30 – 19.00	Dinner		
	19.00 – 20.00	Diet part 1	Dietitian	2
	20.00 – 20.10	Break		
	20.10 – 20.45	Diet part 2	Dietitian	3
	20.45 – 21.00	Personal plan for next week	DSN/dietitian	
2	18.00 – 18.30	Welcome back: So how did it go?	DSN/dietitian	
	18.30 – 19.00	Dinner		
	19.00 – 19.30	Insulin, insulin action and insulin injection	DSN	4
	19.30 – 20.20	Diet part 3	Dietitian	5
	20.20 – 20.45	Blood glucose correction	DSN	6
	20.45 – 21.00	Personal plan for next week	DSN/dietitian	
3	18.00 – 18.30	Welcome back: So how did it go?	DSN/dietitian	
	18.30 – 19.00	Dinner		
	19.00 – 19.50	Diet part 4	Dietitian	7
	19.50 – 20.10	Hypoglycaemia (the lows)	DSN	8
	20.10 – 20.45	Making sense of blood glucose monitoring and adjustment of insulin dose	DSN/dietitian	9
	20.45 – 21.00	Personal plan for next week	DSN/dietitian	
4	18.00 – 18.30	Welcome back: So how did it go?	DSN/dietitian	
	18.30 – 19.00	Dinner		
	19.00 – 19.30	Planning for physical activity	Dietitian	10
	19.30 – 20.00	Sick-day rules	DSN	11
	20.00 – 20.20	Travelling	DSN	12
	20.20 – 20.50	Family/friends and lows and highs	Dietitian	13
	20.50 – 21.00	Where to from here	DSN/dietitian	
Optional session	21.00 – 21.30	Alcohol, drugs and diabetes (optional)	DSN/dietitian	14

One month after completion of the education programme, those assigned to the intervention group visited the DSN and dietitian for a clinic review. They were subsequently contacted by text message on months 2, 4 and 5 post-education and invited to report any difficulties they might be experiencing, such as hypoglycaemia and hyperglycaemia. The control group continued with routine care as before.

Data collection is ongoing for this study and will be reported once all analysis is complete. This article reports on the lessons learnt from running the education programme within the study, and possible issues to consider for future development of adolescent-oriented structured diabetes education.

Ethical approval

Ethical approval was obtained from the Central Office for Research Ethics Northern Ireland. Research governance was then obtained from each individual hospital trust in accordance with their respective procedures.

The education programme

The structured education programme was developed from the Berger programme being provided in Germany and tailored to the needs of adolescents (Mühlhauser et al, 1987).

Page points

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This programme was chosen as it has been ongoing for more than 25 years and was used in the development of the DAFNE programme.

The programme is called CHOICE (Carbohydrate, Insulin Collaborative Education) and includes the following materials:

- A curriculum guide for planning and organising sessions.
- Meal plates depicting standard meals.
- Illustrations of individual portions to construct customised meals.
- Worksheets to be completed during each teaching session to aid participation and understanding.
- Teachers' answers to the questions.
- Flash cards to promote dialogue during teaching sessions.

For participants there is an A5 folder with unit inserts designed to accompany the teaching and a customised daily log-book. Each session included an evening meal that was used to give the participants supervised experience in assessing carbohydrate content and insulin requirements.

Results

This study facilitated collaboration across seven hospital sites within both paediatric and adult care settings. A number of issues emerged during education of the intervention group, which presented challenges in ensuring that the trial ran according to protocol. These are discussed in detail below.

Poor mathematical comprehension

As with most diabetes education programmes, participants were required to calculate their carbohydrate intake at meal times and adjust their insulin dose accordingly. This process requires each adolescent to understand and be able to undertake minor mathematical equations, such as division or multiplication, accurately. Unfortunately, some participants were unable to divide or multiply even simple sums and became embarrassed or disinterested as a result. The issue of mathematical literacy is not new and was highlighted by the Department for Children, Schools and Families (Nunes et al, 2009).

In an effort to allay the fears of those involved and reduce embarrassment, a simple card listing carbohydrate values and required insulin dosage was created. This provided participants with a clear indication of how much insulin should be taken for varying amounts of carbohydrate. This tool was created for a variety of carbohydrate : insulin ratios (1:10, 1:15, 2:10 and 2:15) and worked well.

Poor motivation and active disruption of the group

As with all diabetes education, it is imperative that those involved are motivated to engage with the educational programme. Poor motivation can exist for many reasons and

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1. The process of insulin adjustment and carbohydrate counting requires each adolescent to become proficient in recognising and estimating the amount of carbohydrate within their portion size and adjusting their insulin dose accordingly.
2. The most effective way to capture the attention of reluctant attendees was by goal setting, utilising the leisure activities they most enjoyed and explaining how improved glycaemic control could lead to greater achievement.
3. Once an adolescent highlighted insulin adjustment as a conflict issue, arrangements were made to contact their parents and reassure them about insulin adjustment. This proved beneficial, with parents subsequently assisting in the insulin adjustment process.
4. Of those who attended the education programme, only five failed to return after week 1, suggesting that once an adolescent was engaged they were committed to the entire programme.

is widely acknowledged to be a contributing factor in poor glycaemic control (Delamater et al, 2001). The process of insulin adjustment and carbohydrate counting requires each adolescent to become proficient in recognising and estimating the amount of carbohydrate within their portion size and adjusting their insulin dose accordingly. To become competent in this skill, each adolescent must be willing to practise estimation and engage in insulin adjustment.

This proved difficult for a small minority, whose only reason for attending the education programme was parental pressure. It was therefore necessary for the educator to highlight the benefits of the programme to ensure engagement. The most effective way to capture the attention of adolescents who were reluctant to participate was by goal setting, utilising the leisure activities they most enjoyed and explaining how improved glycaemic control could lead to greater achievement. An example of this would be to establish what sports or exercise the adolescent engaged in and discuss performance issues and the effect of hypoglycaemia and hyperglycaemia.

Family conflict between adolescent and parent

Adolescents attended each education evening without their parents as per their wishes within a previous focus group analysis, the results of which have been submitted for publication in another journal. Parents were invited to attend a parent information evening before the education programme to enable the educator to explain what the programme entailed and answer any questions parents might have.

Despite the educator emphasising the need for adolescents to adjust their insulin depending on their carbohydrate intake, the issue of parental reluctance to allow change of insulin dose became apparent. Although this was rare, with only a few adolescents reporting conflict, action needed to be taken for these individuals to ensure that they could use the skills and education gained.

Once an adolescent highlighted insulin adjustment as a conflict issue, arrangements were made to contact their parents and reassure them about insulin adjustment. This proved very beneficial, with parents subsequently assisting in the insulin adjustment process.

Recruitment and completion

Recruitment to the study and completion of the 4-week programme presented significant challenges, which were overcome through various methods proposed by the collaborative steering group.

A total of 300 adolescents and their parents were approached to take part in the study, of whom 159 agreed to participate. Difficulties in engaging adolescents in research studies is not uncommon and have been documented previously (Lamb et al, 2001). Those who declined to participate cited issues such as extracurricular activities (e.g. swimming, football), good glycaemic control or lack of transport to the venue.

Only five of those who attended the education programme failed to return after week 1, suggesting that once an adolescent was engaged they were committed to the entire programme. For a small minority the influence of parents in achieving full attendance was essential.

The majority of participants expressed the view that they looked forward to the weekly education sessions. This may have been because sessions were kept as practical as possible to encourage engagement and enjoyment in the learning process. Another reason may have been the opportunity to engage with peers who shared the need to manage the same condition.

Discussion

The need to develop structured diabetes education programmes for adolescents and children with diabetes has been acknowledged by many within the diabetes field (DH and Diabetes UK, 2005). Education programmes have the potential to be very beneficial in improving participants' quality of life as well as glycaemic control (DAFNE Study Group, 2002). For education programmes to be effective it is imperative that consideration is given to the learning styles and differing needs of adolescents compared with adults. This

may require banding of ages to ensure that the needs of both younger and older adolescents are fulfilled. Making sessions practical, keeping them short and using real situations that are relevant to adolescents and their social settings is essential.

Literacy and numeracy are essential tools for the matching of insulin dosage to carbohydrate intake. Inaccurate dose calculation may have detrimental effects on an adolescent's day-to-day life, with the potential for severe hypoglycaemia or hyperglycaemia. In addition, failure to achieve optimal glycaemic control may lead to the development of both microvascular and macrovascular complications in the future (DCCT Research Group, 1994).

The issue of poor numeracy and literacy is not new and has been documented (Nunes et al, 2009). Thus there is a clear need to consider this when developing or implementing structured diabetes education programmes in the future. One possible avenue for exploration is the use of the calculator function on mobile phones or the possibility of incorporating an insulin carbohydrate calculator within blood glucose monitoring equipment. The suitability of carbohydrate counting and insulin adjustment for all adolescents must be considered, as a fixed basal–bolus regimen may be the safest option for some.

Within this study, adolescents attended the education programme alone as per their request within a previous focus group analysis during programme development. The need for parents to remain involved in their child's care as they make the transition from adolescent to adult is well recognised (Schilling et al, 2006; Ellis et al, 2007). There is a need to consider whether the attendance of parents as well as the adolescent at part or all of the education sessions would assist in resolving some of the difficulties identified. However, caution needs to be exercised as attendance of a parent may inhibit adolescents from providing a truthful account of their current practices. In contrast, parental attendance may help to reduce conflict and provide support for those who experience difficulty in either estimating carbohydrate content or calculating insulin dosage.

Despite current evidence of the benefits of diabetes education, many adolescents chose not to participate in the programme when offered the opportunity to do so. Those who refused tended to cite existing social or extracurricular commitments as the main barrier to participation. In a recent study to investigate who participates in diabetes self-care interventions, Thoolen et al (2007) suggest that the major reasons for refusal and drop-out are hesitancy towards research and practical barriers, which would fit with the commitments alluded to. They also highlight level of education as a specific barrier to patient engagement; however, caution must be exercised with this finding as their study involved adult participants.

One potential reason for adolescents' refusal to take part might be that they view the education programme as non-essential as it was only being offered to those diagnosed for at least 12 months. These individuals will no doubt have developed management strategies and behaviours and may be unwilling to engage in new methods of self-care, especially if they deem their current practices to be successful.

The low attrition rate from the programme in the current study suggests that once an adolescent has engaged with the education programme they will complete the entire programme. In light of these findings there is a need to develop new and innovative strategies to engage young people and their parents in diabetes structured education programmes.

The complexity associated with the development and testing of educational interventions such as the one used in this study is well recognised (Medical Research Council [MRC], 2000). The success of the study required the commitment of the diabetes teams from both adult and paediatric settings within each hospital as the population under study ranged in age from 13 to 19 years. The involvement of so many professionals added to the complexity of running the clinical trial, and further emphasised the need to adhere to the study protocol. Regular steering group meetings aided communication, and the identification of one individual per hospital site as a point of contact proved invaluable.

Page points

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2. The issue of poor numeracy and literacy is not new and has been documented. Thus there is a clear need to consider this when developing or implementing structured diabetes education programmes in the future.
3. Despite current evidence of the benefits of diabetes education, many adolescents chose not to participate in the programme when offered the opportunity to do so. Those who refused tended to cite existing social or extracurricular commitments as the main barrier to participation.
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1. No adolescents were involved in the steering group as it was felt that the focus groups undertaken during the development phase offered the opportunity to gain sufficient insight.
2. The need for structured diabetes education has been identified and programmes developed within the remit of adult diabetes care.
3. Parents should be involved in structured education programmes in an effort to assist younger adolescents and improve their understanding of the skills needed to attain improved glycaemic control.

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Although a pilot study had been undertaken before the full randomised controlled trial, unanticipated issues such as those highlighted in this article still presented. These issues were dealt with effectively, primarily as a result of the number of experienced healthcare professionals in the steering group. No adolescents were involved in the steering group as it was felt that the focus groups undertaken during the development phase offered the opportunity to gain sufficient insight. However, in light of subsequent issues that arose during the study and the desire to involve more users and carers in research, it would be worth considering the benefit that users might bring to such a group.

The need to undertake feasibility studies before commencing a definitive randomised controlled trial is supported by the MRC (2000). However, in today's climate of healthcare and research funding cuts, acquiring the funding to conduct a feasibility study may prove difficult.

Conclusion

The need for structured diabetes education has been identified and programmes developed within the remit of adult diabetes care. Unfortunately, to-date there is no tried and tested education programme for children and adolescents. The process of developing and testing a structured diabetes education programme specifically tailored to the needs of adolescents has highlighted a number of issues:

- The need to consider literacy and numeracy is evident, with some adolescents unable to undertake the simplest of sums. All future education programmes need to develop new and innovative ways to assist young people with carbohydrate and insulin ratio dose calculation.
- Parents should be involved in structured education programmes in an effort to assist younger adolescents and improve their understanding of the skills needed to attain improved glycaemic control.
- To entice adolescents to participate in a diabetes education programme, such programmes should be offered at times that do not conflict with extracurricular activities.
- Encouraging engagement earlier after a short period of adjustment to a diagnosis of diabetes may assist in achieving a greater uptake of education programmes and allocate education the priority it deserves.
- The nature of complex interventions tested by randomised controlled trial is unpredictable and complicated. Involvement of all members of the diabetes team, good communication strategies and the commitment of all those involved in recruitment and delivery of the intervention are essential ingredients for success. ■

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