

Implementing a new paediatric structured education programme

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1 Structured education is recommended for children and adolescents with diabetes, but little is known about its provision in the UK.

2 The Dose Adjustment For Normal Eating (DAFNE) programme can improve glycaemic control and quality of life in adults with diabetes, but it is unclear how suitable the programme would be for children and adolescents.

3 A survey of nurses working in paediatric diabetes clinics was carried out to get views on the suitability of a paediatric DAFNE-type course.

4 The DAFNE programme was perceived as one suitable option for educating children and adolescents with type 1 diabetes.

KEY WORDS

- Structured education
- Children
- Adolescents

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Introduction

Structured education is recommended for all people with diabetes; however, few interventions for children and adolescents with type 1 diabetes in the UK have been described. The present study was conducted as part of an ongoing project to develop a new programme for 11–16 year olds, suitable for implementation within the National Health Service. Ninety-five diabetes specialist nurses, working in paediatric clinics, completed a survey examining current provision and design of both ongoing and more formal, structured diabetes education in their centre, as well as their views on the perceived difficulty of implementing the new education programme in their centre. Approximately half of the nurses responding had some kind of formal, structured education in place at their clinic. Overall, respondents perceived the proposed education course as difficult but achievable. In those centres already providing additional, formal sessions, it is necessary to ensure that good practices are shared and that education is evaluated. The proposed education course was thought to be of potential value; however, the potential problems – including parental anxiety, staffing and resource issues, and the suitability of the course for less motivated or mature people – must be overcome.

It is widely accepted that people with diabetes may benefit from formal, structured education. People need skills, knowledge and confidence to implement self-care, to adhere to treatment and to make decisions about the impact of treatment on their daily lives. The National Service Framework for diabetes (Department of Health, 2001) states that

'the provision of information, education and psychological support that facilitates self-management is the cornerstone of diabetes care.'

Further, the National Institute for Health and Clinical Excellence (NICE; formerly the National Institute for Clinical Excellence) recommended that formal, structured education be made available to everyone with diabetes (NICE, 2003). Specific recommendations were also made for children and adolescents both at diagnosis and on an ongoing basis (NICE, 2004).

This education is of special importance for children and adolescents, since glycaemic

control typically declines during this stage of life (Amiel et al, 1986; Mortensen et al, 1998; Dabadghao et al, 2001; Du Pasquier-Fediaevsky et al, 2005). This is thought to occur because of a combination of hormonal changes during puberty and psychosocial factors (Hamilton and Daneman, 2002), such as decreased parental support and non-adherence to the treatment regimen. Daily tasks involved in self-care can conflict with the goals of adolescence, impinging on young people's need for independence and making them feel different from peers, which can result in non-adherence to the treatment regimen.

Education to empower people may be one way of aiming to improve control. However, few interventions have been published in the UK (Hampson et al, 2001). This does not mean that children and adolescents are not receiving any education. For example, Llahana et al (2001) surveyed 66 paediatric diabetes specialist nurses (PDSNs) and found that all provided ongoing education, using a variety of methods including group and individual

Table 1. Structure of formal education sessions across centres providing them (determined from a questionnaire).

Characteristic	%
<i>Number of sessions per year</i>	
1	36.2
2	21.3
3	10.6
≥4	10.7
Variable	14.9
No response	6.4
<i>Length of session</i>	
<1 hour	21.3
1–2 hours	53.2
2–3 hours	17.0
>3 hours	4.3
Variable	4.2
<i>Educators present</i>	
Diabetes specialist nurse	100.0
Dietitian	75.6
Consultant	29.8
Psychologist	21.3
Other	11.6

sessions, activity weekends and fun days. In the authors' experience, a great deal of *ad hoc* education takes place within the clinic setting. What is unclear is the amount and type of formal education that goes on in the UK. ('Formal education' can be defined as optional education sessions that have a written curriculum, have clear aims and last for a predefined period of time, and they are often taught in a group setting).

The Dose Adjustment For Normal Eating (DAFNE) programme

Given the lack of fully evaluated formal paediatric diabetes education in the UK, the authors decided to explore the value of adapting an existing adult programme – the DAFNE programme. This week-long course teaches individuals to adjust their insulin dose to match the carbohydrate content of their chosen meal, allowing individuals to adopt more 'normal' eating patterns. A randomised controlled trial of the adult course found that people had significantly improved glycaemic control and quality of life – which was sustained at 12 months – despite the need

for blood tests and injections at least four times per day (DAFNE Study Group, 2002).

The programme is currently designed for people over the age of 18, but it has considerable potential to be used for people between 11 and 16 years old. They can eat more of what they want, can do activities after school and generally have greater freedom. Against this, they would need to cope with having at least four injections and blood tests per day, which may be especially challenging as it would involve self-management during school time. Further, carbohydrate counting and calculation of insulin dosage may present difficulties.

As a first stage in developing the paediatric curriculum, the authors conducted a survey of UK nurses working in paediatric diabetes centres concerning current educational practices, with two primary goals:

- to establish the current provision and format of paediatric diabetes education in the UK
- to assess nurses' views on the difficulties involved in implementing a DAFNE-type approach in paediatric settings.

Methods

Participants

Surveys were posted to 130 diabetes specialist nurses (DSNs) working in paediatric clinics in the UK. Contact details were obtained from the Diabetes UK register for specialist nurses. Where no details were provided, letters were sent out to the clinic or hospital, addressed to the PDSN. A covering letter explaining the purpose of the questionnaire was included.

Questionnaire

A structured questionnaire was developed based on discussions with the multidisciplinary team, including consultants, PDSNs, dietitians and psychologists. The final questionnaire included a combination of closed and open-ended questions and consisted of two sections:

1. Current provision of education

Twenty-three closed questions covered the current provision of both ongoing and formal education sessions. Nurses were asked to indicate how many of these sessions were held per year, how long they lasted

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1 Nurses were asked to indicate the perceived difficulty experienced in implementing seven Dose Adjustment For Normal Eating programme management tasks in a paediatric setting.

2 Choices were on a 5-point Likert-type scale (1 = 'no problem', 2 = 'fairly easy', 3 = 'difficult but achievable', 4 = 'fairly difficult; would need a lot of support', and 5 = 'impossible; refuse to do it').

on average and who taught the sessions. Questions also covered the provision of specific types of ongoing education, including that taught in individuals' schools, insulin dose adjustment and nutritional guidance.

2. Perceived difficulty of implementing a paediatric DAFNE-type course

Nurses were asked to indicate the perceived difficulty experienced in implementing seven DAFNE management tasks in a paediatric setting (see Appendix 1 for the questions asked on the questionnaire):

- having at least four injections per day (including during school time)
- blood testing before each meal
- working out the carbohydrate content of food
- adjusting insulin dosage
- parents allowing children greater responsibility for self-management
- support from schools
- overall difficulty.

Choices were on a 5-point Likert-type scale (1 = 'no problem', 2 = 'fairly easy', 3 = 'difficult but achievable', 4 = 'fairly difficult; would need a lot of support', and 5 = 'impossible; refuse to do it'). There was also a single open-ended question asking respondents for any other comments concerning the implementation of a DAFNE-type course for 11–16 year olds with diabetes.

Analysis

Data from all returned questionnaires were entered into a computer statistics program

(SPSS version 10, Chicago, IL). Frequencies and descriptive statistics were generated. Further, in order to explore the relationship between current educational practices and perceptions of the difficulties involved in implementing a paediatric DAFNE-type course, a series of *t*-tests was conducted. Data from the one open-ended question were analysed using the qualitative method of thematic analysis (Polit et al, 2001).

Results

Response rate

Ninety-six responses were received (giving a response rate of 73.8%). Responses were distributed across all National Health Service regions in the UK. Seventy-six respondents were PDSNs (79.2%), six were paediatric community sisters (6.3%), four were DSNs (4.2%), two were clinical nurse specialists (2.1%) and eight did not include their name or job title on the returned survey (8.3%).

Paediatric Diabetes Education in the UK

Diabetes education is provided in all centres through a variety of methods. All centres offer ongoing education during routine clinic appointments and home visits. Written material is provided for reference: 76% of centres use their own literature; 80% use material developed by Diabetes UK; and 84% use material developed by drug companies.

Important components of this education are the provision of information to individuals' schools, dietary education and insulin dose adjustment skills:

- **School education:** 90.6% of nurses stated that they always do a school visit at diagnosis.
- **Dietary education:** all centres provide comprehensive nutritional advice on all food groups. Education also includes counting of carbohydrates (36.8% of centres), counting of portions (32.6%) and counting of carbohydrate exchanges (16.8%) in a number of centres.
- **Insulin dose adjustment:** insulin dose adjustment is taught in all centres. Written reference material is provided by just over half of the centres (51.0%). Most centres also teach insulin dose adjustment skills for use during times of illness (90.5%).

Table 2. Perceived difficulty of a paediatric DAFNE-type course (1 = 'no problem', 2 = 'fairly easy', 3 = 'difficult but achievable', 4 = 'fairly difficult; would need a lot of support', and 5 = 'impossible; refuse to do it').

Feature questioned	Valid responses	Mean perceived difficulty	Standard deviation
Increased injections	88	2.97	0.82
Blood testing pre-meal	85	2.73	0.85
Calculating carbohydrates	86	2.93	0.78
Adjusting insulin dosage	86	2.95	0.80
Parents allowing greater responsibility	84	3.35	0.65
School support	84	2.80	0.66
Overall difficulty	84	3.06	0.66

Formal education sessions

Respondents indicated that a programme of formal education is available in 49.5% of centres. The most common structures of these education sessions are displayed in *Table 1*. Sessions are often age-banded (61.7%), and several responses indicated that groups are banded using a primary school–secondary school distinction. Over 75% of these centres provide people with reference material to take away from the sessions.

Perceived difficulty of a paediatric DAFNE-type course

Mean scores from the individual questions fell between 2.73 and 3.35 (*Table 2*), indicating that most responses fell around the ‘difficult but achievable’ category. Parents allowing their children greater responsibility for self-management was perceived as the most difficult to achieve.

Based on these responses, a mean difficulty score over the seven items was calculated for each respondent, again with scores ranging from 1 (‘no problem’) to 5 (‘impossible’). The authors were able to use data from 88 surveys; the remaining eight were deemed unsuitable because they contained missing data for more than one item. Cronbach’s alpha (Cronbach, 1951) was calculated to be 0.76, which indicated acceptable internal consistency of this scale. The mean overall difficulty was 2.97 (standard deviation [SD], 3.48), again indicating that most responses fell into the ‘difficult but achievable’ category.

The authors were interested in the relationship between the current educational practices of centres and nurses’ perceptions of the difficulty of undertaking a DAFNE-type approach in children and adolescents. A series of *t*-tests was conducted between the difficulty scores and a number of items concerning current educational practice. Nurses working in clinics who currently run formal education sessions gave significantly higher difficulty ratings (mean, 3.10; SD, 0.50) than those working in clinics not currently running such sessions (mean, 2.86; SD, 0.49; *t*, 2.28; degrees of freedom, 86; *P*=0.025; based on all 88 valid responses). However, nurses working in clinics already teaching carbohydrate counting gave significantly

lower difficulty ratings (mean, 2.78; SD, 0.44) than those in centres not teaching carbohydrate counting (mean, 3.10; SD, 0.49; *t*, 0.30; degrees of freedom, 80; *P*=0.004; based on the 82 valid responses with this question answered).

When asked for any other comments, 61.5% of nurses provided information (the results of a qualitative analysis of these results are shown in *Table 3*). Although a number of comments were very positive (such as ‘This does appear the way forward – parents are asking now about the courses’ and ‘[This] sounds like a very exciting and needed project’), the majority of respondents expressed worries and issues to be considered.

The main area of concern was that only very motivated and mature children would be able to cope with the new regimen (such as ‘It would only work really well with very motivated children’ and ‘We need to select motivated families and provide the education and support’). This may link with the worries surrounding school-time injections, eating disorders and parental anxiety, for example. A second theme to emerge related to the practicalities of running a paediatric DAFNE-type course. Several respondents were worried about the amount of staff needed to run such a course, since staffing was already an issue (such as ‘I am the only PDSN for 165 children’ and ‘[there is a need for] more re-education clinics [and] extra appointments or home visits while getting established, [which means] more nurse time initially’).

Discussion

The study has provided some useful results, in terms of both current paediatric education and the potential for a paediatric DAFNE-type course.

In agreement with Llahana et al (2001), the authors found that all centres provided ongoing education to their young patients by means of regular clinic contact and home visits. However, fewer centres had regular, formal education sessions held in addition to this clinic contact. Just under half of the respondents indicated that they had some form of formal, group education in place at their centre. This finding was in accordance with the Audit Commission’s report entitled

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2 The authors were interested in the relationship between the current educational practices of centres and nurses’ perceptions of the difficulty of undertaking a DAFNE-type approach in children and adolescents.

3 Nurses working in clinics who currently run formal education sessions gave significantly higher difficulty ratings than those working in clinics not currently running such sessions.

4 Nurses working in clinics already teaching carbohydrate counting gave significantly lower difficulty ratings than those in centres not teaching carbohydrate counting.

Table 3. Results of a qualitative analysis of nurse responses.

Theme	Number of responses
<i>Worries</i>	
Only motivated families being able to manage	19
Concern over school-time injections	8
Reluctance to test blood or inject more often	6
Omission of insulin or eating disorders	6
Parental anxiety	4
Too much on top of usual stresses of adolescence	3
Weight gain or over-indulgence	2
Making diabetes more visible	1
Enthusiasm for the new regimen wearing off	1
<i>Practicalities</i>	
Staffing resources	9
Need for evening or weekend sessions	4
Need for support from the whole diabetes team	3
Being better suited to older children	3
Course possibly being an intrusion into personal time	3
Randomisation possibly being difficult	1
<i>Positive comments</i>	
General positive comments	11
Improved quality of life	4
Improved provision of dietary information	2
Help with pressures of diabetes	1

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1 The first major concern about implementation is that the approach will only be suited to the very motivated, and therefore alternative (or additional) methods will still need to be available.

2 The second major concern is that nurses in centres already holding formal education sessions perceived more difficulties with implementation than those in centres not providing such sessions, suggesting that these nurses have already experienced problems when running education courses.

Testing Times (Audit Commission, 2000). Most centres only held between one and three sessions per year. Given that the average health district has over 100 young people with type 1 diabetes (British Diabetic Association, 1996), it is unlikely that the current provision will include all patients. Clearly, there is still a long way to go before reaching NICE's goal of structured education being made available to everyone (NICE, 2003).

However, it is encouraging that some centres have formal methods in place for educating children and adolescents with diabetes. Evidently, a great deal of time and effort is currently spent on this education and in producing material. For example, over three-quarters of nurses indicated that reference material given to people was specially produced at their centre. It is of great importance that these 'good' practices are shared and that educational methods are fully evaluated, in order to carry out further research in this area and to develop knowledge about methods of best practice for educating this age group.

Implementation of a paediatric DAFNE-type course

When asked for their opinions on the difficulty of adopting a paediatric DAFNE-type approach, most nurses felt that it would be difficult but achievable. It is promising that nurses working in centres that already teach carbohydrate counting (a key component of the DAFNE-type approach) perceived fewer difficulties in delivering the programme to young people compared with those not teaching carbohydrate counting, implying that this concept may not prove as difficult to teach as was originally anticipated.

There are two main concerns about implementation. First, the approach will only be suited to the very motivated, and therefore alternative (or additional) methods will still need to be available. Second, nurses in centres already holding formal education sessions perceived more difficulties in delivering a paediatric DAFNE-type programme compared with those in centres not providing such sessions. This finding suggests that these nurses have already experienced problems when running

education courses. For example, a number of nurses commented on difficulties in encouraging people to take part in sessions, and the qualitative analysis of additional comments highlighted concerns relating to the extra time and resources needed.

It is important to address these concerns in the development of any education programme and ensure that teaching does not impinge on educators' personal time and resources, since the results of the qualitative analysis suggest that this is one factor preventing centres from running courses at present.

Conclusion

Only half of the nurses who responded to the survey indicated that their centre had a programme of formal education available. It appears that time and staffing issues are common barriers to beginning a programme of formal education. In those centres already holding sessions, much time and effort is put into educating children and adolescents with diabetes. However, in order to carry out further research in this area it is important that ideas are both shared and evaluated.

The DAFNE programme holds considerable promise for improving glycaemic control and quality of life in children and adolescents with diabetes. However, in developing the paediatric curriculum it is important that particular attention is paid to ensuring that the additional demands are carefully considered and do not impinge adversely on staff time. Staff who are already involved in delivering programmes based on carbohydrate counting have considerable expertise and much to offer on further development of the curriculum. The programme does involve concepts that are difficult for younger people to understand. Consultation between specialist nurses, other health professionals and teachers is therefore essential in order to facilitate communication of these difficult concepts and to promote school and family atmospheres conducive to good management. ■

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1 The Dose Adjustment For Normal Eating (DAFNE) programme holds considerable promise for improving glycaemic control and quality of life in children and adolescents with diabetes.

2 The programme does involve concepts that are difficult for younger people to understand.

3 Consultation between specialist nurses, other health professionals and teachers is therefore essential in order to facilitate communication of these difficult concepts and to promote school and family atmospheres conducive to good management.

Appendix I. A section of the questionnaire, covering the perceived difficulty of implementing a paediatric Dose Adjustment For Normal Eating (DAFNE)-type course.

The adult DAFNE regimen requires the use of multiple injections of insulin to match carbohydrate intake.

Q In your experience, please indicate with a tick below how difficult/easy you feel your children aged between 11 and 16 years would find learning and implementing this regimen.

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

Q Thinking about the following questions, please tick how difficult/easy you feel this age group would find it to adapt to the DAFNE programme.

A How difficult/easy would they find introducing an extra injection at school?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

B How difficult/easy would they find understanding the carbohydrate contents of foods?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

C How difficult/easy would this age group find adjusting their insulin dose?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

D How difficult/easy would this age group find doing their blood tests pre-meal?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

E DAFNE encourages independence, which for children involves a transition of responsibility for their diabetes care from parent to child. How difficulty/easy do you feel this would be for the parents?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

F Would it be difficult/easy for your local schools to support the child to inject at lunchtime?

- | | | | | | |
|--------------------------|--------------------------|--------------------------|---|-----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| No problem | Fairly easy | Difficult but achievable | Fairly difficult; would need a lot of support | Impossible; refuse to do it | Don't know |

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