

A structured educational insulin pump therapy programme: the views of children/young people and their parents

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Received: 13 August 2012

Accepted in revised form:
15 October 2012

Introduction

Results of the Diabetes Control and Complications Trial (DCCT)^{1,2} have shown that intensive insulin therapy (by insulin pumps: continuous subcutaneous insulin infusion [CSII] or multiple daily injections [MDIs]) significantly lowers glycated haemoglobin levels (HbA_{1c}) compared to conventional injection therapy (1–2 injections/day) and reduces progression to diabetes-induced long-term complications. Extensive research has been conducted to evaluate the clinical use of insulin pumps in patients with type 1 diabetes (T1DM), including children and young people. Currently, there is a good body of randomised controlled trials (RCTs) indicating

Summary

This study aimed to determine the views and experiences of parents and children regarding the training and services they had received at a London teaching hospital, when the child commenced insulin pump therapy; and to inform future services.

Face-to-face semi-structured interviews were conducted with children/young people (n=34) aged 5–17 years, using pump therapy, and their parents (n=38). Interviews were audio-recorded, transcribed verbatim and analysed using established qualitative analytical procedures.

Parents and children/young people had their own concerns on starting pump therapy: constant attachment of the child to an insulin pump and the cannula-insertion procedure respectively, being the greatest concerns. The hospital-based diabetes team supported families to overcome such issues. They provided families with 24-hour telephone contact, contacted schools and nurseries, ran a two-day Pump School at the start of pump therapy and provided ongoing services to ease patients' transition from insulin injections to pumps. The programme and services provided were generally perceived positively by children and parents. However, some limitations were reported and suggestions for improvement were made.

In conclusion, the insulin pump therapy programme was appreciated by the majority of families, and provided children and their parents with support for easier transition from insulin injections to pumps. As the numbers of young people using pump therapy increase, the results of this study can inform the development of similar services, by considering this programme as a model for establishing such a service in other specialised diabetes centres.

Eur Diabetes Nursing 2013; 10(1): 25–30

Key words

insulin pumps; type 1 diabetes mellitus; children; young people

the efficacy of insulin pumps in achieving near-normoglycaemia in adults.³ In children and young people, there is also increasing evidence that insulin pumps are effective in achieving and maintaining glycaemic control and in providing a better quality of life.^{4–7}

Developments in the design of insulin pumps over the past few decades have led to users' preference for pumps over injection therapy to manage T1DM,⁸ and there is now increasing evidence that pumps are positively perceived by patients and offer increased lifestyle flexibility.⁹ However, worldwide, use of insulin pumps is still limited (35% in the USA; 15–20% in France, Sweden and the Netherlands).¹⁰ In the UK,

<5% of patients with diabetes are using insulin pumps, and in children and young people use is even less (0.1%),^{10,11} though this will increase as a result of recent changes to UK National Institute for Health and Clinical Excellence (NICE) guidelines, relaxing the rules by which patients can be selected for insulin pump therapy.^{12,13} Currently, many hospitals throughout the world are developing programmes to provide insulin pump therapy services to patients with T1DM.

In the UK, a multidisciplinary, structured education 'pump pathway' for paediatric patients with diabetes has been established at University College Hospital (UCH), London.¹⁴ (Figure 1.) The education

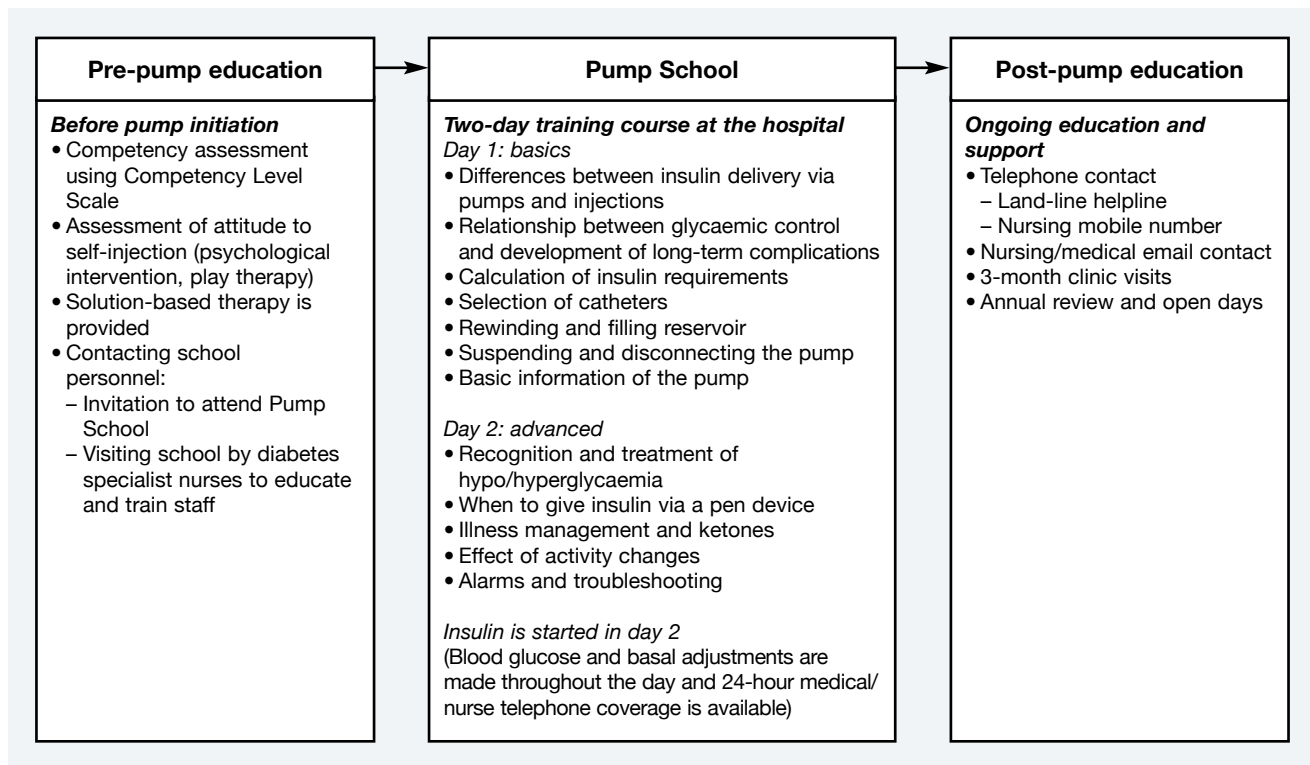


Figure 1. A schematic presentation of the multidisciplinary structured education pump pathway provided for children/young people, and their families, at University College Hospital, London, UK

programme, which commences before patients start pump therapy, comprises a two-day hospital-based training course and ongoing education and support which aim to encourage motivation, flexible self-management and successful transition to insulin pumps from MDIs. The programme was initiated after observing the services provided in leading centres of excellence in insulin pump therapy, and following a systematic literature review.^{14,15} The 'pump pathway' focuses on patients achieving a series of pre-defined competencies, using eight Competency Scale Levels described by Kaufman *et al.*¹⁶ prior to commencing pump therapy, together with an innovative psycho-educational programme (Pump School).

For successful insulin pump use, parents and/or their children must acquire skills and knowledge, which include learning how to insert, disconnect, suspend and program the

pump, the ability to recognise food that contains carbohydrates and successfully measure the quantity of carbohydrate in everyday foods, correct blood glucose levels outside the target range, illness management, and the ability to adjust dosing to take into account exercise and changes in activity patterns. Pump therapy requires patients to perform carbohydrate counting for every meal/snack they consume and to calculate and administer insulin accordingly. This compares with conventional insulin therapy (up to 4 injections/day) where the patients administer fixed insulin doses and consume fixed meals (in terms of content and timings). Therefore, learning carbohydrate counting is an important skill required of patients using insulin pumps.

Insulin pumps are pager-sized devices which are connected to the body via plastic tubing. This tubing ends with a fine cannula which is

inserted subcutaneously into the body. The infusion set has to be changed every two to three days and insertion site rotation is necessary to prevent site hypertrophy and subsequent insertion-site failure. Before pump therapy is initiated, patients' attitudes towards injections are assessed, as needle fearfulness has been recognised as an indicator for poor glycaemic control in children and young people.¹⁷ Regardless of age, all children wear a demonstration insulin pump filled with saline to enable evaluation of how they cope with the 24-hour attachment to the device, and to observe any anxiety they might have regarding cannula insertion. If necessary, psychological intervention and/or play therapy for younger children are offered. Psychological intervention might include supporting patients to combat their fears, and may also include aids to ease the process, such as use of devices

Age range (years)	No. in each group	Gender	Diabetes duration (years)	Duration of pump therapy (months/years)
<5	4	Male: 1 Female: 3	Range: 2–4 Mean: 2.6	Range: 5 mths – 3 yrs Mean: 1.4 yrs
5–7	2	Male: 2 Female: 0	Range: 3–4 Mean: 3.7	Range: 1–4 yrs Mean: 1.9 yrs
8–12	23	Male: 15 Female: 8	Range: 4–11 Mean: 6.7	Range: 5 mths – 5 yrs Mean: 2.5 years
13–17	13	Male: 7 Female: 6	Range: 3–14 Mean: 9.2	Range: 2–7 yrs Mean: 3.7 yrs

Table 1. Characteristics of children and young people, classified according to age range, as reported by children/young people and/or their parents (n=42)

helping with subcutaneous cannula insertion, simplifying the process and easing pain. In some cases, parents also wear a saline pump to experience how it feels to be attached to the device.

Once the health care team is satisfied with the pump 'trial' (e.g. how families coped with the cannula insertion procedure and being attached to a pump) and on achieving the targets identified in level 5 of the Kaufman Competency Scale, two or three families of age-matched children are invited to attend, together, a two-day Pump School course at the hospital (Figure 1).

On commencement of pump therapy, there is close monitoring of blood glucose levels and basal adjustments are carried out. Families and children are also instructed on how frequently they should check blood glucose levels and 24-hour nursing/medical telephone cover is provided during this period. Families are contacted at least once daily in the first two weeks to give them a period of settling down and to consolidate their knowledge. During ongoing therapy, families can contact the medical team by phone or email. In addition, three-monthly regular clinic visits are arranged for face-to-face evaluation and follow up. An annual review and open days are also organised, where many families gather and additional

information, education and support are provided.

Managing diabetes for children/young people using insulin pump therapy requires an integrated and coordinated service delivered by a multidisciplinary team to maximise treatment outcomes. To our knowledge, this is the first study that explores the perspectives of children and parents using the insulin pump services provided at a major teaching hospital. Knowing how the services are perceived by the families will help inform health care providers seeking to improve services and will identify gaps in current service provision, leading to enhanced user satisfaction and optimum treatment outcomes.

Methods

All children and young people (n=65) receiving insulin pump therapy at UCH London, and their parents, were regarded as eligible for this study. A recruitment package containing a cover letter attached to a reply slip, information leaflets and consent forms, was sent to them two weeks prior to their clinic appointment. The interview schedules were devised following a literature review and preliminary fieldwork with the diabetes team. Different versions of all documentation that could be readily understood by the target age group (children aged 5–7 years,

children aged 8–12 years, young people aged 13–17 years, parents of children aged 5 years or older and parents of children aged <5) were prepared. Ethical approval was obtained from the Joint UCL/UCLH Biomedical Research (R&D) Unit and the Joint UCL/UCLH Committee on the Ethics of Human Research, Committee Alpha.

FA undertook face-to-face, semi-structured interviews with each child/young person and parent(s) separately whenever possible, either at home or at the hospital, to gain independent views. For children aged <5 years, parents only were interviewed. Consent to audio-record the interview was requested. Interviews took place between August 2008 and July 2009.

Audio-recorded data were transcribed verbatim. A qualitative themed approach comprising a mixture of framework analysis and grounded approach was undertaken for data analysis. The computer package, MAXQDA 2007, was used to assist with data management. An iterative approach comprising constant comparison was used throughout data analysis, in which the data were constantly revisited after initial coding until no new themes were emerging.¹⁸ To ensure reliability, the first six interviews were coded by members of the research team independently, and the results compared. Data from the children's and parents' interviews were analysed separately to enable identification of the perspectives and experiences of each.

Results

The study aimed to determine the views and experiences of families when the child commenced insulin pump therapy. Forty-two families agreed to participate in the study (the interviews were conducted with 38 parents and 34 children/young people). (Table 1.) The duration of therapy ranged from five months to

five years. Clearly, this raises the issue of the ability of some of the younger children to recall their initial experiences. However, similar views were obtained from the majority of participants regarding the effectiveness of the service in supporting families whose children are on insulin pump therapy, regardless of the date they started receiving the service.

Initial worries and concerns regarding using insulin pumps

The most frequently cited worries for parents prior to commencing therapy were having a cannula permanently inside their child's body and fear of using the device. Such fears arose from worries about the technology, or fear of making mistakes in use (e.g. pressing the wrong buttons).

Reliance on technology concerned parents at the start of insulin pump therapy, with associated fears of the pump's reliability. Other parents worried that the pump might interfere with the child's daily activities or present problems to the child due to its cumbersome size and weight (these were particular concerns for parents of younger children).

All children's worries were focused on the insertion of the cannula. The diabetes clinical team used different strategies to support families and reduce their stress before starting therapy, such as wearing dummy pumps, suggesting relevant reading material and general reassurance.

Participants' views about the structured multidisciplinary insulin pump programme

Telephone contact. The majority of parents (n=33), with agreement by many children (n=9), reported that contacting the diabetes team by phone was helpful, especially at the commencement of insulin pump therapy, when the contact was 24 hours/day, including during night-times.

'He had a stage where his sugars were really high and I could not get them down. That was the time when I phoned them up and that was when I was literally broken down and they were very good. I found that the support from the nurses was the best.' [Mother of a boy aged 11 years; interview no. 18, lines 278–81.]

That this 24-hour service was not provided routinely was an issue for some parents:

'...if it is an emergency you can't always get hold of the diabetes team on the phone. I have had an experience where I needed to speak to a paediatric endocrinologist on-call and there was no paediatric endocrinologist, just a paediatric registrar who actually knew nothing about diabetes. So that is not very useful.' [Mother of a girl aged 15 years; interview no. 23, lines 252–3.]

A delay in receiving a response to calls/messages, especially in an emergency, or that staff contacted were sometimes unable to answer questions or queries, had also been a concern.

One child reported losing confidence after receiving an incorrect dose of basal insulin during initiation of insulin pump therapy.

School contact. School contact on initiation of therapy by the diabetes team was highly valued by most respondents (parents: n=25; children/young people: n=11), as school personnel were able to respond to emergencies. Further contact, especially when the child changed schools, was also appreciated. For children who started insulin pumps while studying at secondary school, where they were expected to undertake management responsibilities themselves, contact with school personnel may occur after the child had already started treatment with an insulin pump. In other instances, the hospital nurses did their best to contact the school, but school personnel were

uncooperative, diminishing the usefulness of the service. Some participants (parents: n=5; children/young people: n=3) thought that school personnel lacked confidence in their knowledge, even after they had received training. In one family, parents thought that the information provided to school personnel was excessive, and beyond that needed for the care of their particular child:

'I felt that they explained too much, and what I used to tell the nursery staff to do is 5 steps "do this, do this, do this" and they followed that. However, there was something like a 7-page document which the hospital presented to them which was great, but the fact is that my daughter is only at the nursery twice a week, and she is only there for about 3 hours a day, so it was not really that relevant.' [Mother of a girl aged 2 years; interview no. 5, line 255.]

Pump School. Most of the parents (n=29) and almost half of the children/young people (n=16) thought the training provided at the hospital, during a two-day Pump School, was good and helpful, as they were taught how to use the pump and had the opportunity to practise. Wearing a demonstration pump was useful for the parents, allowing them to experience how it felt to wear a pump. Other positive views with regard to the Pump School were the value of sharing the training with, and meeting, another family in a relaxed environment which facilitated the asking of questions.

Some less positive views were articulated by two families whose children were the first to receive the Pump School service. They reported either not bonding well with the other family attending the training or that too much emphasis was given to some aspects rather than those perceived as more useful.

'And all of it, the training and everything, was ridiculous, you know, it was

Service	Suggestions to improve services	Other suggestions
Telephone contact	<ul style="list-style-type: none"> Extend to out of hours and weekend access to all, rather than just new users 	<ul style="list-style-type: none"> Every child with diabetes should be given a pump from diagnosis There should be a regular support group at the hospital (i.e. regular meeting for families with children using pumps) More support should be given to families which are new to diabetes and pump therapy than to families who have been dealing with diabetes for a longer duration Shorten pharmacy waiting time for drugs For families with 2 children with diabetes, it would be preferable to start CSII together Families would rather the service is provided locally, so they wouldn't have to travel to London Parents should be more involved in developing the care plan with the diabetes team Hospital needs to provide more practical sessions rather than lecturing Improve blood checking service (make waiting shorter; staff should acquire skills to deal with the children when withdrawing blood; follow Great Ormond Street Hospital policy of 2 staff members to distract the child) Allowing someone to check for blood in the clinic Inform families using injections at University College Hospital, London, about the existence of pump therapy as a treatment option for children and young people
School contact	<ul style="list-style-type: none"> Target support when children move between schools Assess knowledge and confidence of school nurses/staff to provide appropriate support Avoid switching to pump therapy when moving to secondary school as a less supportive setting 	
Pump School course	<ul style="list-style-type: none"> A 3-day rather than the present 2-day Pump School might be helpful Help for families to prepare themselves before they actually receive the pump, so they are not shocked by the amount of information provided on the training day Training could also include a debrief and revision session, perhaps in a second week. Always include families with children of similar ages in a training session Focus on language children can understand 	
Other support services	<ul style="list-style-type: none"> Shorten waiting time to see consultants Focus and opportunity to discuss issues important to parents/young people. A problem for parents when staff are perceived to be busy Preferable if all appointments (psychologist, consultants, or dietitians) are on the same day (so child would have less absence from school) 	

Words in **blue** refer to issues mentioned by both parents and children. Words in **red** refer to issues mentioned by children and young people only.

Table 2. Suggestions/recommendations to improve services provided by the hospital diabetes team, as reported by parents (n=38)* and children/young people (n=34).** (N = number of participants. *Data are missing from 2 parents; 15 reported that they don't have any recommendation/suggestion because the services were excellent. **Data are missing from 8 children/young people; 19 children/young people reported that they don't have any recommendations/suggestions because the services were excellent)

like an hour spent “press this button, press that button”. For example, we asked about dual wave or square wave boluses and they were like “we don't know, you have to do an experiment”. [Mother of a girl aged 12 years; interview no. 4, lines 649–52.]

One child felt that too much of the talking and the vocabulary used was aimed at parents, rather than at them.

It was apparent from the analysis of the transcripts that the policy of conducting each Pump School with two or three families of age-matched children was not always followed. Most parents and children/young people valued participation with other families, as this allowed mutual support, sharing of experiences and enabling children to communicate with peers having a similar experience.

Further support. Following Pump School, all families were scheduled to meet with the diabetes medical consultants every three months for follow up, monitoring and support. Most respondents were satisfied with the opportunity provided in these appointments for parents and children/young people to raise and discuss issues important to them. In particular, the consultations with diabetes nurses were highlighted as helpful. When offered, meetings with dietitians, psychologists and play therapists were also appreciated.

The opportunity to contact diabetes consultants or nurses by email, for instance, for double checking calculations, or to send blood glucose readings for dose monitoring/adjustment, and the receipt of timely replies had been helpful for 15 parents.

‘The diabetes nurses at the UCH have set up one email so you send an email in the hope that somebody will pick it up – that sort of thing.’ [Mother of a boy aged 16 years; interview no. 24, lines 327–8.]

Recommendations for future services

Fifteen parents and 19 children/young people made no further suggestions or recommendations, reporting high levels of satisfaction. The suggestions that were provided by participants are summarised in Table 2.

Discussion

Identifying the concerns of parents and children when pump therapy commences is crucial to enable health care providers to deliver the appropriate support and to ease the transition from pens and needles

to pumps. In this study, the most worrisome issue for some parents and children was the insertion and presence of cannulae, and wearing the device. Similar worries were identified in an earlier study.¹⁹

Most of the feedback from both the children and their parents regarding the hospital-based services received was positive. The nurses in this study were considered excellent at educating school and nursery staff about the children's condition, and how to help with managing their condition in the school. Educating and training school personnel are important, as research has shown that children with diabetes who were cared for by trained school personnel had better therapeutic outcomes than those who were cared for by untrained staff.²⁰

While there are clear benefits for two or more families to attend Pump School together, group activities do not suit everyone, and within the constraints of resources some families will prefer and require individual training.

A need for ongoing psychological support at the hospital was highlighted. An audit, carried out by the diabetes team to explore parents' views of creating psychological groups as a part of the paediatric service at the hospital, highlighted the interest of the majority of parents and the need for consultation with service users when developing such a service.²¹ The importance of integrating the medical care with educational and psycho-educational interventions for children and young people with T1DM was highlighted in a systematic review conducted by Hampson *et al.*²²

In the UK, NICE has recently changed its guidelines to allow greater flexibility for initiating therapy, so that children (aged <12 years old) no longer need to experience therapeutic failure with MDIs before receiving a pump, as was previously

the case (i.e. a pump can be employed if injections are considered impractical or inappropriate).¹² This should allow greater uptake by patients of this therapy option, and NICE estimated that 8–15% of adults and children over 12 years, and 15–50% of children under 12 years, will be eligible to start pump therapy in the three to five years following the revised guidelines.¹³ As the number of insulin pump users increases across the UK, more centres will need to offer a service similar to that described here in order to achieve optimum clinical outcomes. An important aspect of this research was that children's and young people's voices, and those of their families, were heard. The results suggest the suitability of using the insulin pump programme service developed at UCH as a model service for other centres.

Acknowledgements

We thank the diabetes team at UCH, London. We also thank all children and their families who participated in the study. Thanks to Kuwait University for funding a PhD studentship enabling this study.

Declaration of interests

There are no conflicts of interest declared.

References

1. Diabetes Control and Complications Trial Research Group. Effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* 1993;329:977–86.
2. Diabetes Control and Complications Trial Research Group. Effect of intensive therapy on the microvascular complications of type 1 diabetes mellitus. *JAMA* 1994;287:2563–9.
3. Pickup J, *et al.* Glycaemic control with continuous subcutaneous infusion compared with intensive insulin injections in patients with type 1 diabetes: meta-analysis of randomized controlled trials. *BMJ* 2002; 324:705–8.
4. Wilson DM, *et al.* A two-center randomized controlled feasibility study of insulin pump therapy in young children with diabetes. *Diabetes Care* 2005;28:15–9.

5. Phillip M, *et al.* Use of insulin pump therapy in the pediatric age-group. *Diabetes Care* 2007;30:1653–62.
6. Weinzimer SA, *et al.* A randomized trial comparing continuous subcutaneous infusion of insulin aspart versus insulin lispro in children and adolescents with type 1 diabetes. *Diabetes Care* 2008;31:210–5.
7. Churchill JN, *et al.* Use of continuous insulin infusion pumps in young children with type 1 diabetes: a systematic review. *J Pediatr Health Care* 2009;23:173–9.
8. Alsaleh FM, *et al.* Insulin pumps: from inception to the present and toward the future. *J Clin Pharm Ther* 2010;35:127–38.
9. Alsaleh FM, *et al.* Experiences of children/young people and their parents, using insulin pump therapy for the management of type 1 diabetes: qualitative review. *J Clin Pharm Ther* 2012;37:140–7.
10. Pickup J. *Insulin Pump Therapy and Continuous Glucose Monitoring*. UK: Oxford University Press, 2009.
11. Department of Health. National Service Framework for Children, Young People and Maternity Services: Core Standards. UK, DoH, 2007.
12. National Institute for Health and Clinical Excellence. Continuous Subcutaneous Insulin Infusion for the Treatment of Diabetes Mellitus: Review of Technology Appraisal Guidance 57. UK: NICE, 2008.
13. National Institute for Health and Clinical Excellence. Continuous Subcutaneous Insulin Infusion for the Treatment of Diabetes Mellitus (Review of Technology Appraisal Guidance No 57): Costing Template and Report Implementing NICE Guidance. UK: NICE, 2008.
14. Thompson R. 'Pump school' – a structured education programme to empower children and young people using insulin pump therapy. *Eur Diabetes Nurs* 2008;5:108–11.
15. Thompson R. The Relationship between Education, Support and the Success of CSII Initiation in Children, Young People and their Families: A Review. City University, 2005. [Dissertation.]
16. Kaufman F, *et al.* Insulin pump therapy in young children with diabetes. *Diabetes Spectr* 2001;14:84–9.
17. Maniatis AK, *et al.* Life with continuous subcutaneous insulin infusion (CSII) therapy: child and parental perspectives and predictors of metabolic control. *Pediatr Diabetes* 2001;2:51–7.
18. Lincoln Y, Guba E. *Naturalistic Inquiry*. San Francisco: SAGE, 1985.
19. Sullivan-Bolyai S, *et al.* Parents' reflections on managing their children's diabetes with insulin pumps. *J Nurs Scholarsh* 2004; 36:316–23.
20. Wagner J, *et al.* Brief Report: glycemic control, quality of life, and school experiences among students with diabetes. *J Pediatr Psychol* 2006;31:764–9.
21. Christie D, *et al.* Attitudes to psychological groups in a pediatric and adolescent diabetes service: implications for service delivery. *Pediatr Diabetes* 2008;9:388–92.
22. Hampson SE, *et al.* Effects of educational and psychosocial interventions for adolescents with diabetes mellitus: a systematic review. *Health Technol Assess* 2001;5:1–79.