

Pump therapy in the management of children and young people with type 1 diabetes

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Article points

1. Access to pump therapy is an essential component to diabetes care.
2. There is a 6.3% annual increase in the number of children under 5 years old who are diagnosed with diabetes.
3. Access to information for young people with diabetes about pump therapy is not forthcoming and this needs to be addressed.

Key words

- Type 1 diabetes
- Pump therapy
- Quality of life

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The INSulin PUmp Therapy group (INPUT) and the UK Children with Diabetes Advocacy Group (UK CWD) are both voluntary support organisations that are increasingly being contacted by parents of children with type 1 diabetes. INPUT has found that interest in pump therapy for children and young people is steadily rising, and has combined resources with UK CWD to administer a survey examining insulin pump use in children and managing diabetes in schools with injections or a pump. This article reports the findings of a study assessing pump therapy use and access, and provides recommendations for improving practice.

Type 1 diabetes is now occurring more often in younger, often pre-school children (DIAMOND project group, 2006). Williams and Pickup (2004) reported a 6.3% annual increase in the prevalence of diabetes among children under 5 years of age, compared to an overall increase of 3.4% across all age groups.

It is well known that glycaemic control during adolescence is unstable due to hormonal variations (Greene, 2001; Hanas, 2006). This has implications for children in the educational setting (especially concerning) cognitive ability, absence through illness and lowered immunity and during school examinations (Aspey, 2001).

Following the NSF for Diabetes' Standards and Delivery Strategy documents (DoH, 2001; 2003 respectively), NICE published guidelines

on the diagnosis and management of type 1 diabetes in children and young people (NICE, 2004). These guidelines focus on the care, management and ongoing needs of children and young people with type 1 diabetes, but do not give specific recommendations for the use of pump therapy, stating that children should be offered appropriate methods to optimise their glycaemic control. This guidance is non-specific, contrasting with the report of the Insulin Pumps Working Group which states that pump therapy 'should be considered for all children and may have to be initiated early in the management of the child's diabetes, even as early as the point of diagnosis' (DoH, 2007).

Thus, there is some discrepancy within the guidelines regarding the correct way forward in using pump therapy in children and young

people with type 1 diabetes. Recent research suggests that over 80 % of children with type 1 diabetes who started pump therapy maintained their use of the treatment 4 years later (Wood, 2006).

Aim

To examine access to insulin pump therapy and the continued use of this treatment in children and young people with type 1 diabetes in the UK.

Method

A questionnaire survey, based on results from a pilot study, comprising both closed and open-ended questions was designed to generate both quantitative and qualitative responses. Parents accessing the UK CWD support website (www.childrenwithdiabetes.com [accessed 24.09.07]) were invited to take part via email, and parents known to the INPUT group received postal invites.

Formal ethical approval for this study was not required as it did not involve an NHS group or entail altering the child's medication or diabetes management. Neither the INPUT group nor the UK CWD hold details of any medical records for people who contact them, as they are purely patient support and advocacy groups. Because of ethical guidelines concerning the right to participate without doing harm to the individual or their diabetes management, it was decided that children and young people would not be asked directly to comment on their experience of accessing pump therapy (British Psychological Society, 2003). In addition, 8 of the 44 children on pump therapy were under 4 years of age, and could not have assessed their experience of accessing pump treatment independently of their parents. For the purposes of the questionnaire children were classed as up to 19 years of age as guided by the NSF for Children definition (DoH, 2004). Insulin pumps included all makes, models and ages of personal insulin pump, including those with integral glucose monitoring sensors.

The data presented in this study are a subsection of another study which will address the issue of type 1 diabetes in the educational

setting and will be published in the next issue of this journal.

Procedure

Parents were invited to participate by email survey on the UK CWD website. Of the 52 questionnaires sent out to parents of children with diabetes, 38 were returned, giving a response rate of 73.1 %. Parents known to INPUT were invited to participate by completing a postal questionnaire and returning it using the SAE provided. Of the 55 questionnaires sent out, 35 were returned by post, giving a response rate of 63.6 %. Of the total questionnaires returned, 44 children were identified as being on pump therapy. The main reasons for this were high HbA_{1c} (>7.5 %), problems with hypoglycaemia and unstable glycaemic control.

Neither the email nor the postal questionnaires asked for the name of the family responding on behalf of the child, thus ensuring anonymity. In the case of the INPUT surveys, the name and address of the child's parents had been supplied to the organisation when parents contacted them about the use of a pump, but it was not known which parents returned questionnaires. A letter explaining the study was supplied with the email and postal surveys.

Sample

The sample in this study was subject to positive selection bias for pump therapy in terms of diabetes treatment, and in terms of the INPUT and UK CWD databases from which the sample was sourced. The sample comprised 24 boys and 20 girls using pump therapy, residing in the UK and attending different hospitals.

Data analysis

The quantitative data was analysed by percentage frequency of responses from the parents. The qualitative comments were analysed using thematic analysis of the content of comments provided.

Pilot study

As little previous UK-based research exists about children and pump therapy, the questionnaire

Page points

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2. A questionnaire survey, based on results from a pilot study, comprising both closed and open-ended questions was designed.
3. The quantitative data was analysed by percentage frequency of responses from the parents.
4. Little previous UK-based research exists about children and pump therapy.

Page points

1. The UK CWD group, INPUT, Insulin Pumpers UK, the Internet and friends were found to provide the majority of the initial information about pumps.
2. In addition to the child having a clinical need for improved glycaemic control with pump therapy, the issue of choice to improve the child's quality of life was important to parents.
3. All respondents said that the pump had been beneficial to both child and family.

design was informed by a qualitative pilot study indicating areas of pump access and diabetes management that a sample of 10 parents of children using pumps felt should be examined. The pilot sample comprised five parents from the INPUT database and five from the UK CWD database who were contacted by telephone or email. This allowed a measure of the validity of the research tool and research method to be assessed prior to use with the main questionnaire. The 10 parents involved identified several areas of concern, see *Box 1*. They were also asked to complete the main questionnaire (see *Box 2*).

Results

The UK CWD group, INPUT, Insulin Pumpers UK, the Internet and friends were found to provide the majority of the initial information about pumps for 31 parents. After accessing information about pump therapy, parents then sought to ask their child's diabetes clinic about its use. Over two thirds of the children (31) in the sample were refused insulin pump therapy by their diabetes consultant on their parents' first enquiry.

Accessing pump therapy treatment

In this sample, 24 parents said that pump therapy was not initiated at their local hospital. Because of this, 19 travelled to another hospital providing a pump service for the treatment

to be initiated and to receive pump education from trained health professionals. The furthest anyone travelled was between 200 and 250 miles.

Of the 38 parents stating who provided their pump training, 12 were trained by the hospital staff, 6 were trained by the pump manufacturer and 20 were trained jointly by their diabetes team and the pump manufacturer.

Parents were asked to give the criteria they felt were most important for a child to use pump therapy. In addition to the child having a clinical need for improved glycaemic control with pump therapy, the issue of choice to improve the child's quality of life was important to parents.

A variety of sources are utilised by parents when they require advice outside of normal office hours about pump treatment. The availability of advice for pump users was important, with 32 parents stating they had 24-hour access to a trained paediatric nurse if required, and 27 having 24-hour access to a pump-trained nurse if problems arose.

Q: *After using a pump for 6 months, do you feel contact with your diabetes nurse is (less/more/same)?*

When asked about the frequency of contact with the diabetes nurse, half of the parents said they contacted their child's diabetes nurse less in the 6 months following initiation of the treatment.

Q: *Do you think having a pump has been beneficial to your family? (yes/no/same as with injections)*

Respondents have shown that they regard pump use positively. All respondents said that the pump had been beneficial to both child and family.

Choice and involvement

With the availability of a variety of pump systems, the issue of choice is highlighted. Seventeen parents in the sample were able to choose the pump their child preferred, with 33 parents stating that choice was important. However, 27 parents were given no choice of pump make or model.

Interestingly, 30 parents would not have

Box 1. Areas of concern regarding pump therapy as identified by parents from the pilot study.

- Accessing pump therapy treatment, including distance travelled to hospitals providing an insulin pump service, and having to change hospitals (causing conflict with the original diabetes team) and requiring support from INPUT or UK CWD.
- Reasons given by diabetes teams at the child's own hospital regarding the lack of availability of pump therapy.
- Sources of pump information, both prior to using the treatment, and once it has been initiated.
- Parents' criteria for children starting pump therapy in the absence of NICE guidance specifically for children.
- Parents' involvement in the options and choice of a suitable pump for their child, and in the child's diabetes care plan.
- Quality of life issues, including the benefits witnessed by parents when the child treats their diabetes with a pump and night-time hypoglycaemia.

taken the option of pump therapy at the time of diagnosis of their child's diabetes. Over half of parents felt diagnosis would have been too soon to initiate this treatment option for themselves and their children. Similar numbers of parents both agreed (24) and disagreed (20) that using pump therapy from diagnosis would have been difficult and traumatic for the child.

Parents were asked if they were aware of and involved in their child's diabetes care plan. Only four parents were aware of their child's diabetes care plan, had a copy, and had been actively involved in deciding its content.

Quality of life

Almost all parents stated that the use of pump therapy had improved both the child's quality of life (43), and all said that the quality of life of the whole family had improved.

Discussion

The hospital diabetes team was the source of initial pump information for 13 parents in the sample. The main sources of information about pumps for children were from voluntary groups, the Internet, friends, or books, rather than the NHS. This begs the question, are all children who are eligible for pump therapy for whom it may benefit being informed? In the past, some clinicians have felt that pump therapy is not suitable for children because of the use of complex technology, and the perceived risk of ketosis (discussed in: Nebesio and Eugster, 2006).

This survey shows that 31 of the 44 children taking part were initially refused pump therapy by their diabetes consultant at their parents' first enquiry, although this finding cannot be generalised to those children who are not part of the INPUT or UK CWD groups.

However, the findings of this study could suggest that those parents who are not so empowered or enabled may take 'no' as an answer, rather than pursuing this treatment option to gain a pump trial to assess any improvements in glycaemic control.

A number of comments were provided by parents regarding a lack of availability of pumps for children, mainly due to clinicians' concerns

about the age of the children. However, it has been shown that pumps can be started at any age, providing the family has a supportive, pump-trained paediatric diabetes team (Lipman et al, 1989). In fact, as long as the child fits the NICE (2003) criteria for pump therapy to be initiated, there is no reason why this treatment

Box 2. Open and closed questions regarding pump therapy that comprised the questionnaire.

Closed questions

- Did your child's diabetes team explain insulin delivery system options? (yes/no/not applicable)
- Were you actively involved/consulted about the delivery system/regime your child used? (yes/no/not applicable)
- If not, would you have liked to have been involved? (yes/no)
- Are you aware if your child has a diabetes care plan? (yes/no)
- Do you have a copy of your child's care plan? (yes/no)
- Was pump therapy initiated at your local hospital? (yes/no)
- Were you 'pump trained' by hospital staff/pump company staff? (tick as appropriate)
- Were you able to chose which make of pump your child could have? (yes/no)
- Do you think it matters whether you have a choice of pump? (yes/no)
- Given the option of using pump therapy from diagnosis, would you have taken it? (yes/no/don't know)
- Would using a pump from diagnosis have been too soon, having insufficient knowledge of diabetes? (yes/no)
- Would using pump therapy from diagnosis been too traumatic at the time? (yes/no)
- Have you ever needed advice about the pump out of office hours? (yes/no)
- After using a pump for 6 months , do you feel contact with your diabetes nurse is (less/more/same)
- Do you think having a pump has been beneficial to your child? (yes/no/same as with injections)
- Do you think having a pump has been beneficial to your family? (yes/no/same as with injections)

Open-ended questions

- How did you first hear about pumps?
- Did you have any problems accessing pump therapy for you child?
- If pump therapy wasn't available at your local hospital, how far did you travel to access the treatment?
- If you need advice about pump issues out of hours, where would you get it?
- What were the main reasons for your child starting pump therapy?
- What do you think the criteria for a child going onto an insulin pump should be?
- How has pump therapy affected your child?
- How has pump therapy affected your family's quality of life and routine?

Page points

1. None of the parents complained at having to travel to access pump services from non-local hospitals.
2. Only 4 out of the 44 parents had a copy of their child's diabetes care plan.
3. Owning the care plan and understanding what is achievable has been shown to improve glycaemic control in children with diabetes.

should not be an option.

Although some children travel to non-local hospitals to access pump services, the issue of fully trained health professionals in this treatment is key (DoH, 2007). Everett and Kerr (2000) reported that health professionals do not always take up pump training due to reasons such as a lack of experience with the treatment, lack of availability of time to train in its use, or lack of individuals available using the treatment to practise their skills. None of the parents complained at having to travel to access pump services from non-local hospitals where health professionals were trained in the treatment. However, the need to travel to a non-local hospital could be an issue or burden for some families.

On the issue of pump education, one parent commented:

'It doesn't take too long to get to grips with the pump if you have good initial training.'

This highlights the importance of the quality of training regarding pump success and should have a bearing on the question of who ultimately becomes responsible for training children to use pumps.

Parents were asked who they went to for information if their child had a problem with their diabetes management using pump therapy outside of the hours of their hospital diabetes clinic. Most parents (30) needing out of hours advice do not turn to voluntary groups such as INPUT or UK CWD, but contact their diabetes consultant or nurse, or the hospital paediatric ward/helpline. The perceived need for a 24-hour pump service for children with diabetes has deterred some diabetes clinics from initiating pump treatment in the belief that it will create more work for them (Davis and Wilson, 2004). However, following initiation of the treatment, health professionals, children and their families will encounter situations requiring skills which are mastered in the learning process. Thus, the longer the individual uses pump therapy, the more able they are to deal with any problems (Wilson, 2003).

In 2003, NICE estimated a possible 1–2%

of people with type 1 diabetes accessing pumps in the UK, despite figures outside the UK estimating more than 20% (Selam, 2006). It is thought that numbers in the UK will eventually exceed the NICE estimates, especially as the current paediatric pump users become part of the adult population of pump users (DoH, 2007).

Parents were asked if they would have taken the option to initiate pump therapy in their child from diagnosis, and only 14 parents said that they would have. Reasons for this were that, given the benefit of hindsight, initiation of a pump at diagnosis would have been difficult due to the parent and child's lack of knowledge of diabetes at the time, and it being too traumatic, given the impact of diagnosis of a chronic disease. The *National Service Framework for Diabetes: Delivery Strategy* (2003) states that:

'A care plan is at the heart of a partnership approach to care and a central part of effective care management.'

Only 4 out of the 44 parents had a copy of their child's diabetes care plan. However, there may be a greater number of parents actively involved with their child's care planning and decision-making, but are not aware that this is what is happening during clinic visits.

It is true that some parents and children may not wish to be consulted and involved in their care (Cooper, 2002). However, as diabetes is dependent on self-management, it should be encouraged so that the child takes more control of their self-care as they grow older (Hamson et al, 1999). This emphasises the importance of giving the family and child a paper copy of their care plan and discussing it with them so the diabetes team, the family and child, are each aware of their role. Owning the care plan and understanding what is achievable has been shown to improve glycaemic control in children with diabetes (Tamborlane and Ahern, 1997).

Study limitations

The main potential problems with the study were the two different mediums used to administer the questionnaire: email and postal,

it is possible that this may have introduced a confounding factor between the two groups in terms of response. However, response rates for the questionnaires were very similar from each group: 73.1% email surveys, 63.6% postal surveys, suggesting that the mode of administration was not a confounding factor.

Conclusion

The aim of this study was to examine access to insulin pump therapy and the continued use of this treatment in children and young people with type 1 diabetes in the UK. A number of issues have been raised which affect access to this treatment option. Access to initial information about pump therapy has been shown to be predominantly from voluntary groups, with only 13 parents acquiring information from NHS sources. A large number of children have also been refused pump therapy treatment by their diabetes consultant at first enquiry, with 33 parents reporting various reasons for this. In addition, 19 parents had travelled to another hospital to access pump therapy treatment for their child. The main reason for using a pump was an $HbA_{1c} > 7.5\%$. The majority of parents (40) also felt they had not worked with their child's diabetes team in producing a diabetes care plan. This study has shown that the use of pump therapy in children and young people allows choice, flexibility, and an improved quality of life, in addition to improving clinical outcomes. These conclusions have been interpreted into a list of recommendations for current practice which are outlined in Box 3.

Pump therapy, in the view of the authors, is a successful and necessary treatment option for children and young people with type 1 diabetes. ■

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Box 3. Recommendations for practice.

- It is recommended that diabetes teams facilitate information about insulin pump therapy for children and their parents when the child may benefit, for example, where there is an $HbA_{1c} > 7.5\%$.
- It is suggested that NICE guidance in the use of pump therapy in children and young adults should be part of diabetes service delivery. This is currently under revision.
- Pump training opportunities could be utilised by diabetes health professionals to increase the number of hospitals with pump trained staff offering a pump service as the use of this treatment grows.
- It would be helpful if parents were actively involved in their child's diabetes care plan as part of the diabetes care alliance. A copy of the care plan could be given to parents and/or the child.
- Diabetes teams may benefit by ensuring they are familiar with the variety of pumps now available.