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Family preferences for home or hospital care at diagnosis for children with diabetes in the DECIDE study

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Abstract

Aims A diagnosis of Type 1 diabetes in childhood can be a difficult life event for children and families. For children who are not severely ill, initial home rather than hospital-based care at diagnosis is an option although there is little research on which is preferable. Practice varies widely, with long hospital stays in some countries and predominantly home-based care in others. This article reports on the comparative acceptability and experience of children with Type 1 diabetes and their parents taking part in the DECIDE study evaluating outcomes of home or hospital-based treatment from diagnosis in the UK.

Methods Semi-structured interviews with 11 (pairs of) parents and seven children were conducted between 15 and 20 months post diagnosis. Interviewees were asked about adaptation to, management and impact of the diabetes diagnosis, and their experience of initial post-diagnosis treatment.

Results There were no differences between trial arms in adaptation to, management of or impact of diabetes. Most interviewees wanted to be randomized to the 'home' arm initially but expressed a retrospective preference for whichever trial arm they had been in, and cited benefits relating to learning about diabetes management.

Conclusions The setting for early treatment did not appear to have a differential impact on families in the long term. However, the data presented here describe different experiences of early treatment settings from the perspective of children and their families, and factors that influenced how families felt initially about treatment setting. Further research could investigate the short-term benefits of both settings.

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Introduction

Type 1 diabetes mellitus affects 25 199 children in the UK, with 2694 diagnosed annually [1]. The diagnosis of Type 1 diabetes during childhood has a significant effect on the child and the family, including an adverse psychological impact [2,3]. Diagnosis in the UK typically results in the patient spending about 3 days in hospital to stabilize blood glucose levels and to receive diabetes education, although home management of Type 1 diabetes in children has been successfully implemented. Little is known about the effectiveness and acceptability of home and hospital management in relation to initial coping and longer-term outcomes [4,5]. Most studies have not found differences in clinical outcomes between children receiving early treatment at home or hospital [6]; one study found lower HbA_{1c} in children treated at home [7]. Actual practice varies widely and, for example, in Sweden, Finland and Japan, hospital stays can last for 3 weeks, whereas in the USA not all children are hospitalized and for those that are, the average length of stay is around 2 days. In the UK, initial care is often largely hospital-based due to limited community care resources, although this has been changing in favour of greater home management in some areas [8,9].

The Delivering Early Care In Diabetes Evaluation (DECIDE) study was a pragmatic randomized controlled trial (RCT) that examined the effect of home or hospital management at diagnosis of childhood diabetes on longer-term physical, psychological, social and economic outcomes. All participants were formally diagnosed in a hospital setting, and were then invited to participate in the DECIDE

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What's new?

- Home or hospital treatment settings for children newly diagnosed with diabetes vary widely but little is known about the impact of early treatment settings on children and their families.
- Treatment setting was found to have no long-term impact on adaptation to, management of or impact of diabetes on children and their families.
- Families tended to express a preference for home treatment when offered an option at diagnosis.
- Retrospectively, families tended to prefer whichever treatment setting, home or hospital, they experienced and identified benefits in terms of learning about diabetes.

trial if they met study criteria [10]. Participants were randomized to either home or hospital management: hospital management included a planned stay in hospital for a minimum of 3 nights; home management was provided by diabetes nurses undertaking home visits for a minimum of 3 days and, dependent upon which centre they were in, families also had access to out-of-hours telephone support.

The primary outcome of the trial was HbA_{1c} at 24 months after diagnosis. Secondary outcomes included measures of psychological adjustment, coping and adaptation to the diagnosis, diabetes knowledge, socialization and independence, and satisfaction with service provision. In addition, acceptability of initial home or hospital treatment for children and their parents was investigated. A cost–benefit analysis was conducted to determine the relative cost of early treatment at home compared with hospital. For further details, see the trial protocol [10]. This article reports on the acceptability and impact of home and hospital treatment trial arms from the perspectives of children and parents.

Research design and methods

To investigate the acceptability and impact of the two trial arms, face-to-face semi-structured interviews were conducted 15–20 months post diagnosis with 11 parents/pairs of parents and seven children. Interviewees were purposively sampled to include a mix of male and female children, and children in three different age groups: 0–7, 8–12 and 13–17 years. The range of ages of child interviewed was from 7 to 16 years. Age groups rather than exact ages of children are reported in the findings section, to preserve anonymity. See Table S1 for a summary of the interview profiles. Participants were interviewed in their homes; children and parents were interviewed separately. Multicentre approval was granted by the Research Ethics Committee (REC) for Wales (07/MRE09/59). Site-specific approval was granted by local RECs at all trial sites and all participating acute trust research and development departments. Parents of children with newly diagnosed Type 1 diabetes provided written informed consent and where appropriate, children provided written assent. The study sponsor was Cardiff University.

Topics in the semi-structured interview included: experience of diagnosis, acceptability of treatment received immediately after diagnosis, short- and longer-term coping and adaptation to diabetes; management of diabetes, and impact of diabetes on the child and family. Interviews were digitally recorded, and fully transcribed. In the first stage of analysis, data were coded by a qualitative researcher using NVivo 10. The first four interviews were double-coded by a second researcher and any themes in which coding matched < 95% (identified using the coding comparison query in NVivo) were discussed between the researchers to resolve differences. The double-coding was conducted before the remaining interviews were coded, to ensure a robust coding framework was applied to the entire dataset. In all, 40 themes were identified; these were discussed and agreed by the first author and the second researcher. Most themes arose from categories in the interview schedules, such as experiences of initial home or hospital management. Additional themes such as comparing diabetes with 'sicker' people also emerged from the data. A second stage of analysis was conducted in which each theme was summarized in a table, with a separate column for each trial arm, to provide an overview and comparison of each theme by trial arm. This second stage produced a summary of each theme but included enough detail of the variation in interviewee responses to prevent impressionistic bias of each theme in the reporting of data. The two columns were then compared to identify any differences in each theme by trial arm. Once these differences were summarized and written up, the table of themes was further reviewed to identify any additional themes that might help explain the results of this trial arm comparison.

Results

Most of the 40 themes that emerged reflected typical issues in managing diabetes, such as negotiating responsibility between the child and parent, and managing diabetes in settings such as school, holidays and sleepovers. Adaptation to diabetes was similar for both trial arms, taking several weeks or months: for example, families in both arms reported using telephone support in the weeks and months after diagnosis as they adjusted to living with diabetes. These results did not differ by trial arm. There was considerable variation in interviewee responses, but these typically depended on factors such as child age, personality, lifestyle and family dynamics. Four of the 40 themes summarized in the table during the second stage of analysis were identified as displaying significant differences between trial arms. These were: 'preference for home treatment', 'preference for hospital treatment', 'early home treatment' and 'early hospital treatment'. Within the 'preference for hospital treatment' theme there was a clear distinction

between initial and retrospective preferences. The data reported here therefore concentrate on preferences for and experiences of post-diagnosis treatment, compared by trial arm. After this trial arm comparison was conducted on these four themes, further themes were identified which might help explain these results. These themes were: 'attitude to research – child', 'attitude to research – parent' (this theme included how treatment preference affected decisions to participate in the trial), 'getting on with it', 'comparison to sicker people', 'initial hospital experience at diagnosis', 'telephone help' and 'support received – professionals'. Data on the main four themes comparing trial arms, plus 'attitudes to research', are presented in three sections: (1) the preference of parents and children on entry to the trial, (2) interviewees' experiences of receiving early treatment and (3) interviewees' retrospective preferences at the end of trial participation. Further themes identified to help explain the comparative findings are reported separately at the end of the results section. Ages of children indicated in quotes are age group at diagnosis.

Initial preferences for home or hospital treatment

Six of the eleven parents interviewed expressed an initial preference for home treatment. Of the remaining parents, three only reported their child's preference (which was to go home in all three cases), one said they had no preference and one gave an ambiguous answer. Parents' own reasons for wanting to go home often concerned disruption to family life, such as childcare of siblings and transport difficulties if the child stayed in hospital:

> We was hoping that we could come home 'cos we also have two other children and it's very hard to manage that.
>
> (Parent of child aged 0–7, hospital arm)

Several parents were also conscious of the stress the child was under by being in hospital in addition to the stress of the diagnosis. Three parents consented to take part in DECIDE because their child had a preference for going home and participating in the trial provided an opportunity to do so:

Parent Then the option was put to us whether we could actually take part in the study and there would be a 50/50 chance that we could manage the treatment at home.

Interviewer
OK

Parent Which is what (child) wanted to do so that's when my husband and I agreed that we would take part in the study.

(Parent of child aged 13–17, home arm)

In addition to these family-related factors, three parents also commented that they were conscious of the necessity of managing the diabetes properly and safely immediately after diagnosis.

Six of the seven children interviewed said they had wanted to go home. All but one parent also reported that their children had an initial preference for home treatment. The primary reason for children's preferences was a dislike of the hospital environment, which could be unfamiliar and frightening:

> I was relieved cos I didn't have to stay in the hospital cos I don't really like hospitals they scare me, so when we went home it was a great relief, a lot more calming as such.
>
> (Child aged 13–17, home arm)

Two children specifically decided to participate in DECIDE because it gave them an opportunity to go home:

Interviewer
Can you remember being approached about the study?

Child Yeah.

Interviewer
Can you remember what happened?

Child [Nurse's name] came up to me and asked me about it.

Interviewer
Right.

Child The only reason I did it at the time was because it gave me a chance of getting out of hospital cos I'd never been in hospital and I just didn't like it at first.

(Child aged 13-17 years, hospital arm)

Two children also mentioned the idea of remaining in hospital as making them feel 'down' and 'sad' and a third said they felt 'lucky' they could go home.

Experiences of post-diagnosis treatment in hospital and home settings

Parents reported different types of support received in the hospital setting, including: nurses showing children and parents how to administer injections; nurses monitoring that children were self-injecting properly; staff providing information, reassuring parents and explaining things clearly; and knowing that staff were nearby if the parent had a question. Parents said little else about the hospital setting, although five commented that they were very happy with the care their child received.

When describing experiences of hospital treatment, children commented on an initial dislike of aspects of the hospital environment such as being woken up by nursing staff for monitoring, noise on wards and hospital food. However, children made largely positive comments about their hospital stays:

> When I went to the hospital it was a lot easier 'cos I had a lot of people coming to me, they were all sort of very nice.
>
> (Child aged 8–12 years, hospital arm)

Children described positive aspects of being in hospital as: attention from hospital staff who were nice, having support easily accessible if needed, feeling reassured that help was nearby, staff providing information leaflets, staff answering questions, nurses showing them how to do injections, nurses watching children self-administer to check they were injecting properly, reminders about when to inject, receiving dietary advice, being left alone and having time to think, and being free from parental supervision. As a result, children felt they learned how to manage diabetes well in this environment:

> I thought being in hospital was much easier to deal with it than being at home, 'cause when you're in hospital you feel like you've always got support there like, you can ask anything and like you know nothing bad is going to happen cause if it did, the hospital staff are there to help you … I think I was in for about a week in hospital and every day they come and tell me a bit more information about diabetes and when to have my needles and when to do blood tests … being in hospital was so much easier to deal with it all.
>
> (Child aged 13–17, hospital arm)

In the home arm, two parents reported finding the idea of learning about and coping with diabetes by themselves daunting initially:

> [The] first few days it was quite, quite stressful. It was a lot to take in … it was a lot to learn. I didn't realize I didn't really know much about diabetes.
>
> (Parent of child aged 8–12, home arm)

Two parents reported feeling entirely or largely confident that they could manage at home and two said they felt reassured by help from nurse visits and telephone support. Similarly to the hospital arm, parents in the home arm reported that their setting was a good environment for learning about diabetes. Home arm parents mentioned the benefit of home treatment in terms of being able to take things slowly, managing diabetes in their normal environment, feeling more comfortable at home, facilitating early independence in managing diabetes and being in control early on:

> The thing is we were going to learn it quicker at home weren't we, we had to learn it … it was difficult coming home straight away but I think it was the right thing because at some stage you would have had to do it.
>
> (Parent of child aged 0–7, home arm)

Children who were in the home arm mentioned receiving help from nurse visits but tended to emphasize early independence and control. One child felt it was easier to get used to having diabetes at home and another said they were in control sooner and adapted quicker, and felt confident. Further, a child commented that they would have to cope on their own anyway:

> … and then the next morning they just came here to show me how to use me needle, how to, they were like 'Do you need help now?' and I was just like 'No'. I just wanted to do it myself, I didn't want anyone to help me. I just wanted to learn myself 'cause I know that what's the point if she's just going to show me then I'm going to have to learn anyway, so from the very beginning I've done all my bloods myself, all my injections myself.
>
> (Child aged 13–17 home arm)

One child reported feeling nervous at first but then felt confident after a couple of days.

Retrospective preferences for hospital and home treatment

Interviewees also tended to emphasize the benefits of learning about diabetes when comparing trial arms and tended to refer to this when expressing their retrospective preferences, which were for their own trial arm. These preferences represent interviewee perspectives between 15 and 20 months post diagnosis.

Four parents talked about preferring the hospital setting in the end because they had support immediately available and they learned about diabetes better:

> At first I wanted to come home. I didn't want to stay in hospital because you'd rather, you're thinking 'Oh I'd rather be in your own home' but at the time when we were, I was glad because I had everyone around to help me and if I was concerned, instead of ringing up all the time on the phone or having to go down there, so we just had all the staff around us and they were really helpful and told us what was what when we didn't know.
>
> (Parent of child aged 8–12, hospital arm)

Two parents also reported that they would have been more frightened about managing diabetes if their children had gone home.

Children in the hospital arm tended to comment on having an initial preference for home but then realizing the benefits of being in hospital. Children described adapting to the hospital environment after their initial dislike of it, often due to finding staff helpful. Children most commonly reported the benefits of staying in hospital as having easily available support to learn how to manage diabetes:

> I wanted to go home because I felt more comfortable there but after being at hospital for couple of days I thought oh it was much better there cos it was a lot more handy and you know it was easier for me to learn things.
>
> (Child aged 8–12, hospital arm)

Parents in the home arm did not change their preferences and said they were happy with their trial arm allocation. Parent preferences were based on: child preferences for the home arm, practical family considerations, and their experience of home treatment as facilitating early independence.

Children in the home arm reported feeling more comfortable at home, similarly to their initial preferences, and expressed the benefits of developing independence and control in managing diabetes in this setting:

> 'Cause you're at your house, you … feel like you're in control of it [diabetes] from the start and therefore you don't have to go from being nurtured in a hospital to then suddenly controlling it yourself. I think if you have to control it from the word go then you adapt to controlling it a lot quicker.
>
> (Child aged 13–17, home arm)

To summarize, most participants expressed a preference for the home arm initially but hospital arm parents and children changed their preferences retrospectively. Ultimately, both trial arm groups tended to identify the benefit of their treatment setting in terms of learning about managing diabetes effectively. The emotional demands of both the diagnosis and learning about diabetes management were also evident in both parent and child responses in each treatment setting, as was the initial dislike of the hospital environment for children and managing practical family matters for parents.

Explaining changes in preferences

The final stage of analysis was to identify further themes that might explain the tendency for families to have a retrospective preference for their own trial arm. Two explanations emerged from these themes: the quality of care received by participants and adopting a positive attitude as a coping style.

Barring a small number of exceptions, children and parents in the DECIDE trial had positive experiences of efficient, competent and sensitive care received from professionals such as nurses and doctors, in both hospital and community settings, face-to-face and by telephone. Staff were described as 'lovely' and efficient, and as educating families and reassuring them.

Further, several interviewees reported adapting to diabetes by focusing on the positive, either by 'just getting on with it' or by comparing their own situation with that of others in the hospital with more serious conditions:

> When we went into hospital and you see the different wards I thought 'Oh gosh, this could've been something that we might not have been able to manage' so you've just got to take it as it comes.
>
> (Parent of child aged 8–12, hospital arm)

The implications of care received and participant coping styles for treatment preferences are discussed below.

Discussion

The main finding from this study is that home treatment was initially more preferable for most families when presented with a choice, but that both settings were acceptable for families who experienced some stress in each setting but also identified ways in which they benefitted, particularly in terms of learning to manage diabetes. Interviewees had a retrospective preference for whichever trial arm they were in and would identify benefits they thought they had received by being in that arm. This overall finding has striking similarities to a healthcare preference study conducted by Lawton *et al.* [11] on education programmes for adults with newly diagnosed diabetes where preferences changed over time to align with whichever intervention was actually received. Moreover, interviewees in both studies were able to be specific in identifying the benefits of the programme they received, citing their intervention as contributing to their learning in some way. Of course, each interviewee only experienced one trial arm and so could not make a fully informed comparison with the other trial arm. Furthermore, interviewees in DECIDE and in the study reported by Lawton *et al.* [11] received a well-established and well-delivered intervention that would increase the likelihood of satisfaction with an intervention and therefore preference for it.

The wider literature also indicates that preferences are not always stable over time and can be influenced by broader factors such as memory and context [12]. One influence on retrospective preferences in the DECIDE study may have been the coping style adopted by some families to 'just get on with it' or to compare their situation with that of 'sicker people', which emphasized the positive. This coping strategy may have led children and parents to focus to a greater extent on positive aspects of their situation, including services received, after diagnosis. Adopting a positive attitude as coping style in response to a diagnosis of diabetes has been reported elsewhere in the literature [13].

These data indicate that receiving either home or hospital treatment at diagnosis of Type 1 diabetes in children does not appear to make a difference to the long-term adaption, management and impact of diabetes on children and their families at 15–20 months post diagnosis. There were differences in the acceptability of home and hospital treatment at the point of diagnosis, with a clear preference expressed for home treatment, especially among children. However, these preferences were not stable over time. Initial preferences were based on which setting would be most comfortable (for children) or on practical considerations of family life (for parents). In their actual experiences of early treatment, families in both trial arms reported benefits in terms of learning about diabetes management: at home, families had a chance to become independent quickly; in hospital they had immediate access to support and resources. Both staying in hospital and going home also produced some stress, because hospital environments and managing alone at home can both be difficult. In their retrospective preferences, interviewees tended to discuss the benefits for each setting in terms of learning to manage diabetes, with home arm interviewees discussing control, independence and quick adaptation, whereas hospital interviewees commented on the availability of resources such as support from staff. Familiarity with only

one treatment setting, satisfaction with services and coping strategies all may explain why interviewees tended to express a preference for their own trial arm.

Main trial outcomes have yet to be reported. These findings provide important perspectives from children and families receiving care in different settings and indicate that families have initial preferences for home settings but in practice find both treatment settings acceptable. If one treatment setting is found to have better glycaemic or psychological outcomes, these findings indicate that either setting would be acceptable to families. If treatment settings are found to have equal outcomes and when children with newly diagnosed Type 1 diabetes do not require hospitalization, these findings can inform provision of care alongside factors such as available local resources [14] and the preferences of medical staff. Data reported here also suggest that if patients and families are offered a choice of home or hospital treatment, personal circumstances may indicate which would be preferable. These factors in deciding treatment setting will vary by local and national context; the detail included here about family preferences and experiences may help clinicians and practitioners apply these findings to their own contexts.

Further research could investigate in more depth the relative short-term benefit of each setting with respect to acceptability and appropriateness for families. Relevant factors suggested by these data include: the child's attitude to the hospital environment; level of desire to manage diabetes independently; anxiety in children and/or parents about managing diabetes independently at home; the need for reassurance and confidence-building from medical staff; the ability of parents to manage family life at the same time as accompanying or visiting a child in hospital; and how conducive the home environment is to learning about diabetes management. Future research could also investigate whether offering choice reduces overall stress for families, or whether being offered a choice may be stressful in some cases. Lastly, informing families that children and parents tend to be happy with either treatment setting and that they report successfully learning about diabetes in both settings could be useful information for families encountering any treatment setting option at the point of diagnosis.

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Competing interests

None declared.

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References

1 National Paediatric Diabetes Audit Project Board, Royal College of Paediatrics and Child Health. *National Paediatric Diabetes Audit Report 2011–2012*. London: Royal College of Paediatrics and Child Health, 2013.
2 Bowes S, Lowes L, Warner J, Gregory JW. Chronic sorrow in parents of children with type 1 diabetes. *J Adv Nurs* 2009; **65**: 992–1000.
3 Spencer JE, Cooper HC, Milton B. The lived experiences of young people (13–16 years) with Type 1 diabetes mellitus and their parents – a qualitative phenomenological study. *Diabet Med* 2013; **30**: e17–e24.
4 Lowes L, Gregory JW, Lyne P. Newly diagnosed childhood diabetes: a psychosocial transition for parents? *J Adv Nurs* 2005; **50**: 253–261.
5 Clar C, Waugh N, Thomas S. *Routine Hospital Admission Versus Out-Patient or Home Care in Children at Diagnosis of Type 1 Diabetes Mellitus (Review)*. *Cochrane Database Syst Rev* 2007. CD004099.
6 Jasinski CF, Rodriguez-Monguio R, Tonyushkina K, Allen H. Healthcare cost of type 1 diabetes mellitus in new-onset children in a hospital compared to an outpatient setting. *BMC Pediatr* 2013; **13**(55). Available at http://www.biomedcentral.com/1471-2431/13/55 Last accessed 30 January 2015.
7 Dougherty G, Schiffrin A, White D, Lee Soderstrom L, Sufrategui M. Home-based management can achieve intensification cost-effectively in type 1 diabetes. *Pediatrics* 1999; **103**: 122–128.
8 Lowes L, Gregory JW. Management of newly diagnosed diabetes: home or hospital? *Arch Dis Child* 2004; **89**: 934–937.
9 Agwu JC. Home management versus inpatient care of adolescents with newly diagnosed type 1 diabetes mellitus: a survey of current practice. *Arch Dis Child* 2005; **90**: 547.
10 Townson JK, Gregory JW, Cohen D, Channon S, Harman N, Davies JH *et al.* Delivering early care in diabetes evaluation (DECIDE): a protocol for a randomised controlled trial to assess hospital versus home management at diagnosis in childhood diabetes. *BMC Pediatr* 2011; **11**(7). Available at http://www.biomedcentral.com/1471-2431/11/7 Last accessed 30 January 2015.
11 Lawton J, Rankin D, Elliott J; United Kingdom National Institute for Health Research Dose Adjustment for Normal Eating (DAFNE) Study Group. Is consulting patients about their health service preferences a useful exercise? *Qual Health Res* 2013; **23**: 876–886.
12 Aldrovandi S, Heussen D. Preference stability and memory: two unlikely companions. *Front Psychol* 2011; **2**: 1–3.
13 Lowes L, Gregory JW, Lyne P. Newly diagnosed childhood diabetes: a psychosocial transition for parents? *J Adv Nurs* 2005; **50**: 253–261.
14 Silverstein J, Klingensmith G, Copeland K, Plotnick L, Kaufman F, Laffel L *et al.* Care of children and adolescents with type 1 diabetes, a statement of the American Diabetes Association. *Diabetes Care* 2005; **28**: 186–212.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Summary of interviews.