Children as partners in their diabetes care

Can children understand and share in managing their daily diabetes care? This small study with 24 children aged 3 to 12 years found that they can be highly involved. During interviews, the children and their parents talked about their everyday lives, their views on daily blood tests and insulin injections, food, doctors and nurses, the time when their diabetes was diagnosed, information and support, and how children 'just want to get on with their lives'.

The study found that:

- Some young children understand a great deal about daily diabetes care, the low-sugar diet, how to take and assess blood tests and inject insulin, and how to explain diabetes to other people. Some become very adept early on, others prefer their mothers to manage most of the care. From the start, they need clear positive explanations about the daily routines, and why these are helpful; otherwise the diabetes care can seem cruel and pointless.

- Besides having knowledge and skill, young children can be competent at making choices, managing difference, and being 'normal'. Their main goals tend to be 'just to get on with life' and to have fun with their friends. They need routines that fit smoothly into their everyday life and goals.

- The 24 children and 29 parents we spoke with learn most about diabetes through personal experience, including children's own bodily sensations, and the trial and error of finding out what works best. They tend to feel that they have too much information at first, and too little information later on.

- The small sample reported high levels of satisfaction with the care from the specialist diabetes staff. Yet care from non-specialist practitioners posed very serious problems for most of the children, and school staff varied in how helpful they were.

- Children and parents offer a wealth of information gained through their personal experiences. These could help practitioners and policy makers to raise standards of diabetes health care, working as partners with children and parents.

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Background

There is growing concern in Britain about the rising rates of diabetes, the high personal costs to the 1.3 million people affected, the great expense of treating diabetes and its complications, and the shortage of specialist diabetes practitioners. Type II diabetes mainly affects adults. Type I diabetes starts in childhood and can affect slim fit children with a healthy life style. Unless new treatments are found, they will need to have daily insulin injections all their life. Rates of type I diabetes are rising among young children. Yet very little research has been conducted with them about their knowledge, views and experiences – the topics of this research.

The government aims to empower patients and promote partnership between patients and practitioners. We looked at the ages when partnership can begin.

Aims

* To find out about the views of children aged 3 -12 years on living with diabetes, and sharing their health care in partnerships with adults.
* To explore how much they can share in managing their diabetes care.
* To involve as highly varied a sample as possible, in terms of the ethnicity, socio-economic background, age of the children, and their experience of diabetes.
* To take account of extra difficulties children and parents may meet with at home or school or in their community.
* To provide reports on children's views and experiences for children with diabetes, their parents and carers, health care professionals, policy makers and researchers.
* To learn from and help to promote positive ways of supporting and involving younger children in their diabetes care.

Methods

* We met the children through three hospitals: two in London, one in the outer suburbs. With two groups we chose a purposive (deliberately wide-ranging) sample, and sent them opt-in requests, inviting them to join the project. Families that replied were mainly white and middle class and we met most of them at their home. The third and more diverse group was contacted and interviewed in a diabetes clinic.

* We piloted the interviews. These began by asking about the children's everyday life, their friends, and things they enjoy doing. We asked open questions to encourage them to tell the story of their life and about diabetes. Some children played a game and 11 did a drawing. They all chose a research name. We also observed the three clinics and interviewed two doctors and two nurses. We transcribed the tapes, and analysed them for replies to our questions and for themes raised by the children.

New areas of research

This project is unusual in exploring four fairly new areas of research:
* The views of children aged from 3 years onwards;
* Positive ways in which children can share in managing their care;
* Social problems that arise in everyday life, rather than personal problems within the children themselves or their families;
* Methods of listening to children's own accounts, rather than using tests, or questionnaires, or solely adults' replies.

Early competence

Decisions

Emma gave early examples of making sensible decisions. When aged 4 she knew she could have a little cake at parties, but the nursery staff often forgot. Emma would wait to ask her mother later to remind the staff for next time. Her friend once found a box of chocolates and wanted Emma to share them. Emma refused, as her blood test proved. When she was 5, she arranged with her mother that at parties she could do a blood test and then decide how many sweet things she could eat. Perhaps more complicated than calculating what to eat, is the children's competence in managing to be different from her friends but still to be accepted fully by them.

Needles

DJ was 6, and Nicola 4 when they did their own blood tests and injections, though like other children Nicola preferred her mother to do injections sometimes.

Children vary in what they feel able and willing to do. Alex had needle phobia and at age 11 found injections very hard, as did one of the mothers. When James was diagnosed at age 7, he could do his injections before his mother felt able to. When William was aged 7, he was pleased that a young friend, who also had diabetes, showed him how to start doing injections.

Food and insulin

Food and activity choices constantly revolve around trying to balance blood sugar levels between too low and too high. Jo aged 7 and her mother chose food together for her packed lunch each day. Mr Football aged 9 was expert on calories in types of foods. Children checked calorie details on food or drink packets, and worked out their current blood sugar level against how much energy they might need for the next few hours. Johnny managed an insulin pump and like Jimbo, also aged 11, adjusted his insulin doses to fit his needs.

Understanding

If they went to visit friends, some children did their routines and also explained these. David aged 11 said succinctly: *It's an illness and an organ in your body isn't working, and it's stopped producing this liquid, and you need this liquid to turn sugar into energy, and this liquid is insulin, and so you have to have injections of it. And you can't have so much sugar in your food.*

Moral insight

Jessie aged 6 showed the children's responsible moral understanding when saying 'I'm sure'.

Interviewer: This is my little girl. She's just got diabetes…Can you tell us what we need to do?

Jessie … When she's feeling low you must always give her some sweets, and when she's feeling high you must always, always not give her sweets…

Int: And how would I know if she's high or low?

Jessie: She'll tell you, I'm sure.

Int: Is there anything else I need to do…?

Jessie: Yes, you need to do your blood sugar [she explains how to do so] and then you have to see how high or low you are so you can have some treats or not. So that's how you do it.

Other findings

This short report is mainly about the children's skill and understanding. Yet they also described good care from specialists and dangerously inadequate care from non-specialist practitioners. They talked about the first days when they found they had diabetes and they raised questions about whether hospital or home was the best place for them to be then, if they were well enough to go home. Even it they played a very active part in their care, children did not necessarily want to talk much in the clinics. They described how teachers could be very helpful or very unhelpful. Most of all, the children emphasised how they wanted to be normal and to get on with their lives. They needed devices and routines at home, nursery and school, to help them to do so.

Early conclusions

We aimed to find out if young children can share in their diabetes care and talk to us about it. Their ability to take part in the research demonstrates their ability to understand and take part in managing their diabetes care. They gave clear evidence of their competence, and some parents mentioned their surprise that their children were so able.

Yet although some children can be highly responsible, this does not mean they all either can be or want to be. Each child may vary, sometimes wanting more help, sometimes less, without following a single pattern of growing independence. And they might, for example, be expert with needles or about calories, but not want to talk much with their doctor.

Having found that it is very worthwhile talking with younger children, we plan to do a more thorough project with those aged 3 – 8 years. We will allow more time for participative research methods, such as asking them to take photos and draw maps, or to use toys to explain their points as Jessie was doing when she was quoted earlier.

We also aim to allow time to explore children's differing, sometimes ambivalent views, and we will avoid offering hasty conclusions at this stage.

Children and parents raised serious questions for future research with larger samples:
* Are there better ways to inform them, offer them choices, support them after diagnosis and over the following years?
* How can GPs, A&E and general children's ward staff improve their care?
* How can school and nursery staff become more aware and respectful of the children's expertise?
* How can willing positive partnerships between younger children and adults be encouraged and problems be prevented?

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Reports
For a free e-copy of the 90 page report email ssru@ioe.ac.uk
For printed copies send your order with £10 (free printed copies to interviewees).
There is also a 4 page report for children.

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