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ORIGINAL ARTICLE

Children as partners with adults in their medical care

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Aims: To investigate the seldom published views of children with type 1 diabetes about their condition and ways in which they share in managing their medical and health care with adults.

Methods: Semi-structured, tape recorded interviews, during 2003, with a purposive sample of 24 children aged 3–12 years who have type 1 diabetes and who attend two inner London hospitals and one hospital in a commuter town.

Results: The children reported high levels of understanding, knowledge, and skill gained from their experience of living with diabetes and constantly having to take account of the condition and their paediatrician's guidance. Their key goals were to be "normal" and "just get on with their lives".

Discussion: The interviews showed that children's experiences of diabetes tended to enable them to make informed, "wise" decisions in their own best interests, even at a young age. They achieved a complicated balance between the sometimes competing goals of social health "being normal" and physiological health in controlling glycaemia. Their competence supports approaches in children's rights and in policy makers' aims that people with diabetes—including children—gain more knowledge, skills, and responsibility for their own care in partnership with healthcare professionals. Consent is usually considered in relation to surgery; however the children showed how they constantly dealt with decisions about consent or refusal, compliance with, or resistance to their prescribed treatment. Their health depends on their informed commitment to medical guidance; more research is needed about the daily realities of children's committed and responsible co-management of their chronic illness.

In Britain, around 15 000–18 000 children have insulin dependent diabetes, though the incidence of this is rising, particularly in the early years. Good glycaemic control reduces the risk of serious later-onset complications that affect 50% of people with diabetes, and carry very high personal and economic costs.¹

"Freedom from complications is a shared responsibility between patient and professional...when there is a discrepancy between the goals of patients and professionals, those [goals] of the patient and their parents are more likely to affect the outcome of the treatment."²

Effective diabetes care therefore depends on a converging of clinical and personal goals through patients' informed, willing partnership,^{3–5} although there has been little research about children's views and goals or their ability to share in daily management of a serious chronic condition.^{6–8} Psychological research generally questions rather than endorses practitioners' trust in their patients as responsible partners, because it mainly involves adolescents' and adults' difficulties and morbidity. So this paper is unusual in concentrating on children's views about how they share responsibility with their parents and within paediatrician's guidelines that constantly affect their daily life and decisions.

METHODS

We observed clinics in two inner London hospitals and one in a commuter town. With their consent, we held semi-structured tape recorded interviews with a purposive (deliberately diverse) sample of 15 children aged 3–6 and 10–12 years (table 1), and a convenience sample of nine children aged 6–11 years (table 2). Findings from interviews with two paediatricians, two specialist diabetes nurses, and 29 parents are reported elsewhere,⁹ except to note here that parents tended to confirm the children's responses.

Fifteen families were contacted by post with information leaflets and requests to opt into the research, and were interviewed at home. Nine families were contacted and interviewed in a diabetes clinic. Over two thirds of the children were accompanied by a parent when interviewed. The children chose their research names to protect anonymity. With their consent, we asked children about their everyday lives to encourage detailed narrative responses. They held up a red card if they wanted to pause or stop. We asked: "What did you do today? This week? What was the best day of your last holidays? Do you like school/nursery?". We asked about friends, about being the same as or different from friends, about siblings and other relatives, and about parties because these are among the many occasions when sugar is central to celebrations, treats, and rewards. Then we asked, "Do you remember when you first had diabetes? What happened?". The other main themes included understanding and management of diabetes, visiting the clinic, their future ambitions, and how they would advise a newly diagnosed child their age.

Interview transcripts were systematically read and re-read, and analysed for themes raised by the interviewees,¹⁰ such as their views on normality, and for direct and indirect replies throughout the session to the main research questions:

- When do children begin to be able and willing to take an informed share in managing their diabetes care?
- Is it wise or kind to listen to young children and to respect their goals and rights?

Ethics approval was obtained from the three local research ethics committees.

RESULTS

This paper concentrates on the children's responses about being informed partners in managing their diabetes, constantly balancing cooperation with medical requirements

Table 1 Purposive sample; age when interviewed and on diagnosis

	Boys							Girls							
Age when interviewed	12	11	11	11	11	10	10	6	4	12	11	11	6	5	3
Age when diagnosed	10	8	5	4	1.33	7	7	1.25	1.25	10	4	2	1.25	1.25	1.33

with being “normal”. In the quotations, ... denotes words omitted, and numbers in brackets after names denote age.

Understanding diabetes

Fifteen of the 24 children were aged 15 months to 5 years when diagnosed. Some had become very ill and so they had intense experience of the life threatening nature of their condition, through their practical and possibly intuitive knowledge. Moogum (7), diagnosed when she was aged 5 years, said:

“My sister was at home in bed and she was crying because she thought I was dead.”

She added later:

“Everyone when they have a sweet, when I do not be diabetic I used to have everything, and now when I’m at home, my sisters say [high, chanting tone], ‘You’ve got diabetes, you’ve got diabetes’, and then I feel sad and I go up to my room and get in my bed and do nothing.”

Mr Football (9), diagnosed just after his sixth birthday, remembered being frightened at being in a room on his own in hospital, on a drip.

“There was nobody, no one to talk to, there was no little boys...I was almost dead.”

And Jo (7) recalled being diagnosed when she was 4, and her mother changing the sick bowl for her before she went into a coma. They also understood hypoglycaemia through bodily experiences: Maisy (3) demonstrated how she felt “wobbly”, and Jake (4) would say urgently, “Mummy, I’m low *now!*”. He had become more anxious since he had been kept waiting for five hours in A&E until he passed out. These children (through memories of severe hypos and, in some cases, of being so ill when diagnosed) had intense embodied understanding of diabetes.

Needles

The children’s ability and willingness to use needles were not age related. Johnny and Nicola were 4 years old when they did their own blood tests and injections. James, diagnosed when aged 7, could do his injections before his mother felt able to do them. Rezwana (11) and Holly (11) wanted their mothers to do their injections for them, unless they stayed

overnight at a friend’s house. Several children said it hurt less when they inserted the needles themselves. Some of them showed us their equipment and explained their routines clearly:

Simba (7): That one’s heavy [shows equipment]. This one’s empty. The heaviest one might be, yup, you have to do like that...You have to dial it up, like this one I do there...Because there will be insulin inside here and this will be there, so when you dial it up, first you put the needle and shake it, dial it up, then put it in your body, then it will float inside your body and go to the pancreas.

George (11): It’s like a meter and you put something in and you prick yourself and they make the blood and there’s a little bit flashing and you got to put it on like that [showing]... The strip goes in the little slot, which is there and it comes on and you prick yourself with one of these, where are they?... One of these needles, which is [shows it]. And when you’ve done you put your blood on the little strip... If it’s something like 4.6 it’s quite normal. If it’s something like, 3.2 you need to eat something, it’s getting low. And if it’s like 6 or 7 that’s really high.

John Doe (12): I don’t usually increase my dose, like even if it’s been bad, even if it’s like 8 per cent I just can’t be bothered, because I’ll have to remember every level, and I have three injections, each different. But for stuff like, I have two injections of the fast acting, which I just do myself.

Managing diet and insulin

Food choices constantly involve trying to avoid hyper- or hypoglycaemia. At 4 years of age, Nicola knew that “insulin is the key that turns sugar into energy”, having lacked energy for months before being diagnosed. Jake (4) and Jessie (6) knew they needed low sugar diets and became used to discussing higher or lower carbohydrate levels with their parents. Mr Football (9) memorised the carbohydrate counts for many foods. James (10) and Nicola (11) checked carbohydrate 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 and Jimbo (11) and John Doe (12) adjusted their insulin doses to fit their needs, and Johnny had a pump. He explained how he changes his cannula every three days and takes his mealtime insulin boluses

Table 2 Convenience sample; age when interviewed and on diagnosis

	Boys					Girls			
Age when interviewed	11	10	9	7	6	11	7	7	7
Age when diagnosed	9	4	8	4	6	6	5	3	3

What is already known on this topic

- Practitioners are increasingly advised to work in partnership with their patients
- However, research about young people's experiences of living with diabetes is mainly negative, in recording adolescents' morbidity, non-compliance, and needs

"I just press a button and it goes in...I've got to calculate it"

based on carbohydrate counts and what he plans to eat. Johnny's mother confirmed that his friends "were absolutely fascinated" and helped him with his calculations. Jessie (6) indicated younger children's capacity for responsible moral understanding when saying "I'm sure". She was playing with a toy hospital set with the interviewer.

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...

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

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

Interviewer: Is there anything else I need to do...?

Jessie: Yes, [she explains how to test blood sugar and decide if] you can have some treats or not. So that's how you do it.

When Emma was 4 years old, her friend found a box of chocolates and wanted Emma to share them. Emma refused, as her next blood test proved. She could have a piece of cake at parties, but the nursery staff often forgot and she would wait to ask her mother later to remind the staff for next time. When aged 5, Emma arranged with her mother that at parties she could do a blood test and then decide how many sweet things she could eat.

Goals

More complicated than calculating carbohydrates is the children's social competence in being different from their friends, such as when Emma refused chocolates or Johnny worked his pump, while they managed to sustain friendships and to be accepted as "normal". When asked open questions about their everyday life, their likes and dislikes, the children talked about two main goals: "just to get on with life" and to be "normal". They resented "boring" diabetes care—snacks, blood tests, and injections—that interrupted activities they enjoyed, and they tended to talk of the inconvenience rather than pain.

Edwina (12): Sometimes I can't be bothered...I could be in the middle of something fun, and my mother goes, "It's time to do that thing," gets on my nerves.

Some children criticised other people's negative attitudes that unnecessarily created problems for them, such as teachers who would not take them on a school outing (Edwina) or who made them miss playtime when they had their snack (David), or Jo's friend's mother who refused to invite Jo to sleepovers at her house. Some children protested. For example, David moved to a friendlier school, and when

What this study adds

- From around 4 years of age children start to understand the principles and take responsible moral decisions about managing their diabetes
- Evidence based practice in partnerships with young patients who have a chronic condition needs a research literature about the competencies of younger children

James's teacher gave him a prize of a bag of sweets, he and his mother returned it and asked for a proper prize.

DISCUSSION

We are cautious about generalising from this small project, although, whereas large surveys are required to support generalisations, for instance, about the average 6 year old's capabilities, only a few examples are needed to show, as our research does, that at least some "ordinary" young children with diabetes are well in advance of child development theories about stages of ability. From about 4 years, the children began to understand the principles of controlling diabetes. They could make informed and "wise" decisions in their own best interests¹¹ and, as other research has shown, their competence to consent developed through experience rather by age.¹² Consent is usually considered in relation to surgery, but consent/refusal in sometimes hard decisions about whether to resist or comply with their diabetes regime were part of the children's daily life. Their health depends on their informed commitment.

The findings are confirmed by clinicians, including reviewers of this paper, as familiar to most paediatricians. We have five reasons for publicising seemingly unremarkable findings. (1) Children's views are seldom published in paediatric journals. (2) Their competencies are also seldom publicised; research reports tend to concentrate on problems and morbidity. (3) There is therefore a tendency, instead of regarding children's views and competencies potentially as research evidence that can reliably inform practice, to regard them as anecdotal (literally: unpublished; implicitly: of doubtful validity). (4) In contrast to the immense number of research papers about medical treatment of children's bodies, there are very few papers about younger children's cooperation with medical guidance and goals,² in a partnership that is especially vital in chronic conditions. (5) The research literature needs to include more reports about children's views and experiences of being informed and trusted by their parents and paediatricians if it is to reflect the realities of 21st century clinical practice.

Adult-child communication tends to be dominated by often misleading age-stage theories and methods,¹³ that under- or overestimate many children's abilities. Paediatricians are advised, for example, to talk directly to children, but should they respect the preference of many capable children that their parents speak for them? Policy makers urgently want people with diabetes to gain more knowledge, skills, and responsibility for their own care,¹ which depends on partnership between practitioners and patients, "and greater patient autonomy and self-sufficiency".¹⁶ Child-adult partnerships that put children "at the heart of" policy deliberations are also advocated.¹⁷ The RCPCH's first duty of a paediatrician is that "Paediatricians should commit themselves to practise in accordance with the Objects of the College and the UN Convention on the Rights of the Child". And the final duty is to place "the child's best interests at the centre of all clinical considerations".¹⁴ The key

right in the UN Convention is children's right to express views in all matters that affect them, and for "due weight" to be given to their views.¹⁵ Research findings and debate about children's own views, as in this paper, are intended to assist paediatricians in fulfilling this guidance.

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