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TITLE: **Facilitating children's contributions in clinic?** Findings from an in-depth qualitative study with children with type 1 diabetes

Original article

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Structured Summary

Aims
There is a policy drive for children to contribute more directly in clinic visits. However, this has yet to be routinely achieved in practice and relatively little is known to date about younger children's views of their illness and care. This in-depth qualitative study set out to explore the experiences of children ten years or younger living with type 1 diabetes.

Methods
The sample of 17 children was self-selecting from a population of 140 children under 11 years receiving treatment for type 1 diabetes at 2 outpatients clinics in a large, multi-cultural city. Fieldwork comprised home visits, discussion groups and observation in out-patient clinics.

Findings
Children's strong experiential understandings of their condition, the impact of their social position on experiences of care, and their active role in maintenance of the regimen were at odds with how they were positioned, and how the disease was discussed, in clinic.

Conclusion
Findings have implications for facilitating children's contributions in clinic, understanding how ideas about children are reproduced in clinical settings, and supporting clinicians to recognise the capacities and priorities of children living with long-term illness.

INTRODUCTION

Engagement with patients' views and priorities may support patients' informed decision-making, as well as clinicians' exploration of the feasibility of the 'clinically' best option for a particular individual (1). Evidence in adult populations suggests 'patient-centred' approaches can improve patients' experiences (2), possibly even outcomes (3). Likewise, in paediatrics there has been a policy drive to increase children and young people's participation in clinic visits, so that young patients increasingly define the problems and goals for their care (4,5). However, achieving this in practice has proved difficult, and clinicians and young people alike have expressed ambivalence (6, 7, 8).

A rapid increase in new cases of type 1 diabetes in younger children in Europe suggests that by 2020 the proportion of children affected across early childhood, late childhood and early teenage groups will be much more closely matched (9). This study sought to explore the understandings, experiences and priorities of children ten years or younger living with type 1 diabetes, in relation to their illness and care, with a view to informing their greater participation in clinic visits. We know from existing studies that children can have strong experiential understandings of their condition, see themselves as key contributors to their care, and appreciate adults engaging with them in ways that acknowledge this (10, 11, 12, 13). While adults diagnosed with long-term illness seem to mourn a loss of continuity in relation to self and identity (14), children have been found to be more concerned with a threat to their sense of ordinariness in relation to others (15), perhaps because of their diagnosis early in the lifecourse, where there is 'no prior period of wellness, stability, or perceived *normality*' (16).

There may be a policy drive for hearing from children in consultations; however, social studies have shown how children's accounts are frequently regarded as partial, or unreliable especially outside the home (17). These studies have drawn attention to the inequality between the social status of adults and children, in particular children's lack of economic and civic power; and how, particularly in situations when adults have to act as experts on children (for example, as teachers, social workers, or health workers), they may over-emphasise, and hence add to, children's vulnerability, beyond the origins of this in the biology of the youngest children (17). They suggest that views of children which focus on the shortcomings of children's developing capacities in relation to an adult gold standard can detract from what children *can* do, and the impact they have on their own and others' lives (18). For these reasons this study was undertaken from a perspective in which children's competencies are understood to be 'different from' rather than 'less' than those of adults (19) and children regarded as a reliable source of information on their own lives.

METHODS

A qualitative approach was identified as the most appropriate for exploring children's views and experiences (20). The convenience sample of 17 children was self-selecting from a population of 140 children under 11 years receiving care for type 1 diabetes at 2 paediatric diabetes clinics in inner-city, and low income (respectively) areas of a large, multi-cultural city. The researcher was an independent researcher unconnected with clinical teams. Invitations in one of 11 different languages were sent to children's homes. Forty-two information sheets were distributed by the researcher in 12 outpatient clinics over a 4 month period. Children's and carers' consent was sought by the researcher, and participation terminated if children subsequently decided not to take part. Fieldwork comprised 2-4 visits with each child (or set of siblings), mostly at home; participant

observation of at least one clinic appointment (though 2 children requested not because they did not want to be observed during the blood test for their annual review); non-participant observation in waiting rooms; and 2 discussion groups in which the researcher fed back emerging findings for children's comment. In 2 instances the researcher was accompanied on home visits by an interpreter who facilitated communication with mothers. All children spoke English. Children were given a disposable camera to photograph 'the important things' in their lives (21). During home visits the researcher observed and talked with children about their daily experiences of diabetes. When children wished, she used play-based approaches, their drawings or photographs to prompt discussion (21, 22). Children chose pseudonyms. They were given laminated copies of their drawings and a £15 voucher at the end of the project as a thank you.

Home visits were recorded, transcribed and entered into QSR*Nudist software. Fieldnotes were kept on observations in children's homes and outpatients, and copied in preparation for hand coding. The researcher used the constant comparative method to identify themes and patterns, both emerging directly from the data and relating to ideas in the existing literature (23, 24) Negative cases and patterns in relation to structures such as proportion of life lived with the condition, age, ethnicity and gender were actively sought. The sample size achieved data saturation without incurring unnecessary recruitment and demands on service users' and clinical/support staff time.

FINDINGS

Eleven of the 17 participants were aged 8 years or younger; 9 were boys; nearly half had lived most of their lives with a type 1 diabetes diagnosis (Table 1). There were 2 sets of siblings amongst participants (Little Miss Perfect and Trunks; Lisa and Spyro). Lisa and Spyro were the only children on flexible regimens, both had pumps. The researcher made 2 home visits of about 45 minutes for each child; except for one child, who preferred 4 slower paced visits; and 2 instances where mothers preferred the second meeting at clinic. Most visits took place in the living room of children's homes, with mothers or siblings present intermittently, or in a few instances throughout the visit. The researcher observed one clinic appointment for 13 children, and 2 appointments for 2. Children were accompanied to appointments by mothers in all cases except one, where the child lived with his grandmother who took him to clinic, and 2 instances where fathers also attended. Eleven children in total took part in discussion groups.

Table 1 Age, ethnicity and age at diagnosis with participants who have lived with a type 1 diabetes diagnosis most of their lives shaded.

How is the condition understood?

Children from the earliest ages were willing and able to discuss their illness and regimen in terms of their day-to-day activities and feelings. Many had begun to make links between these and bio-medical models of their condition, sometimes with prompts from mothers (table 2.1). Decontextualised queries were on the whole unhelpful: asked why it matters what he eats, Ruben (11) is unclear; later he explains in detail what he would eat if his level was 7 before bed-time. Children's understandings and experiences were embedded in their emotional responses, social relations with others and their position as children – for example, sharing care with adults (mainly mothers), or not always being believed about symptoms or getting access to supplies in schools (table 2,1).

By contrast, in the clinic, the disease was understood at an entity in itself, connected to, but separate from, children's lives, and knowable mainly in terms of physiological data, and mothers' proxy reports of physical symptoms (table 2.2). Care was separated out into social, emotional and physiological components with different practitioners for each. These approaches facilitated doctors' scrutiny of children's physiological well-being while avoiding awkward involvement in the messy details of day-to-day family life: Emma volunteered how a faulty blood glucose meter led her mother to accuse her of lying (table 2.1), which the consultant firmly and carefully passed over by offering a replacement meter. Nurses' engagement with the interface of children's condition with their daily lives seemed to make their role more readily meaningful to children compared with that of consultants (table 2.2)

What is children's role in care?

Children saw themselves as active, reliable contributors to care alongside mothers, with divisions of labour shifting as much in relation to convenience as competency – see Shannon, table 3.1. They used the first person to describe even care completed by mothers, casting their compliance as an important contribution - see Girls Aloud, table 3.1. Processes of learning about the regimen were almost imperceptible, gained through watching and practice. Children presented themselves as resourceful in juggling wider priorities – such as maintaining their ordinariness in relation to others - against an experience of illness shaped almost as much by their position on the life course as the regimen. For example, time is one of the few resources children still have some control over, though this may be decreasingly so (25): Lisa and Spyro debated in detail how to achieve split second reductions in the time needed to deliver a bolus (table 3.1).

By contrast, in clinic, children's position was peripheral. They were discussed for the most part in the third person, and as has been found elsewhere, asked only about non-illness related, though often pertinent, aspects of their lives – mainly by nurses. Those that did make suggestions about care were largely ignored by both parents and clinicians. Most did not see consultations as something to which they could usefully contribute (table 3.2).

Contexts for hearing children's views

The researcher approached children as creditable sources of information on their personal experiences. She emphasised her own ignorance about their lives, and focussed on what children could do and understand. She was explicit that the aim was to hear their views and therefore 'there are no right answers'. She tried to bear this out via affirming responses to children's accounts, and finding small opportunities to give children power over interaction, for example, asking their permission before sitting with them (table 4.1). Children from the earliest ages were largely enthusiastic about describing their day-to-day experiences. Most eschewed role-play based approaches, in favour of talking while drawing or looking at photographs, . This helped them to set the pace and direction of discussion and somewhat redressed the imbalance of power between adult researcher and child participant.

By contrast in the clinic, families had little control over the pace and direction of interaction. Long waits for appointments and little attention to social nicities (clinicians reading notes before turning to greet families, not introducing observers, nor explaining procedures) evoked a sense of the very great value of consultants' time. Communication was framed in bio-medical models of the condition and characterised by a tightly focussed question and answer format (see table 2.2 for examples). Children with sufficient experience to be able to recall the processes of the three monthly clinics understood the consultant's role as adjudicating their 'progress' (table 4.2).

CONCLUSIONS

Children demonstrated strong experiential understandings; and experiences grounded in a view of themselves as key contributors to care, and in their social position as children (10, 11, 12). This was at odds with how they were positioned, and how the disease was discussed in clinic. This may explain why so few children felt this was a environment to which they could contribute usefully; which, in turn, may explain how ideas about children that focus on a perceived deficit between children's developing capabilities and those of adults are reproduced and reinforced in clinic settings (17, 18).

Supporting children to contribute in clinic is likely to involve a combination of acknowledging the dissonance between children's and clinicians' perspectives while finding ways to demonstrate belief in the value and validity of children's views. Drawing on childhood researchers' insights about how research with children is different from research with adults (26), findings suggest three areas for attention :

An explicit and convincing rationale for hearing from children

Clinicians will need to provide a convincing rationale for hearing from children, so that questions are perceived as genuine (rather than a test). It may be helpful if this is explicit about (and clinicians subsequently demonstrate):

- belief in the validity of children's perspectives on their own lives from the earliest ages;
- commitment to the value of this in planning care - not least because children are key contributors to their daily care and have unique insights into how this is affected by their position as children (10).

Children's different ways of communicating, based in experiential understandings

It may help if clinicians try to think of children's capacities as 'different' rather than 'less' than those of adults (19) and seek to engage with their strong experiential understandings by framing discussions in terms of activities and physical sensations (10,12).

The generational imbalance of power, compounded by the doctor-patient relationship

Childhood researchers have argued power does not reside in fixed positions of 'adult' and 'child' but is designated via interaction (27). Other work highlights the importance of respectful and unrushed exchanges with children (6). It may also be helpful to:

- be explicit with children about wanting to understand their viewpoints rather than holding them to account – 'there are no right answers'.
- bear this out by finding opportunities for affirming responses and small gestures which demonstrate how children's input and expertise is valued – for example attentive listening regardless of interruption (27)
- offering children an additional activity, such as drawing, to engage with during clinic as this can help them set the pace and style of exchanges (26).

However there may difficulties with some of these last points. Far from perceiving there to be 'no right answers' in clinic, children in the study understood the consultation to be about exactly this: adjudication of their 'progress'. Some might argue this is amenable to change, that doctors can learn, and demonstrate, willingness to engage in a non-judgemental way. Others suggest there is a more fundamental obstacle: that doctors' social role is not just to heal patients but to arbitrate their efforts at wellness (28); and that the tight, physiologically-focused exchanges of the consultation (at odds with the slow, discursive approaches favoured by children) serve an important purpose: not only to ensure efficient

use of clinic time, but to restrict doctors' surveillance of families' lives by limiting it to the purely bio-medical (29). Some have suggested that this may explain the limited impact of the patient-centred project to date (30).

Findings indicate a framework grounded in social studies of childhood for facilitating children's contributions to clinic. Current patterns of communication across the doctor-child-carer triad may fulfil social functions that mean deep-seated change is difficult. However the framework may complement medical models of childhood in ways that support clinicians in better understanding the capacities and priorities of children living with long-term illness.

Strengths and limitations

Qualitative methods prioritise in-depth exploration of human experience over generalisablity (19). The 17 children who took part in this study provided fine-grained accounts of their daily lives with the condition. Demographics of the sample and details of the setting are provided to inform judgements about potential transferability to other populations.

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