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## **Levers and barriers to patient-centred care with children: findings from a synthesis of studies of the experiences of children living with type 1 diabetes or asthma**

**CurtisTyler, K**

**Background** Past 50 years have seen a sea change in approaches to health care with children, from a time when children were separated from parents while in hospital, to current recognition of the importance of placing the experiences of children and their families at the heart of care. Yet, there is a gap in the evidence about how children's involvement might be best achieved. This study aimed to synthesize findings of children's experiences of longterm illness and, from this, to identify levers and barriers to patient-centred care with children.

**Methods** A synthesis of studies of experiences of children living with type 1 diabetes or asthma.

**Data sources** Eight health and social care databases, bibliography searches and consultation with field experts and first authors of included studies.

**Eligibility** Qualitative studies with children 10 years (mean) and younger on their experiences of living with type 1 diabetes or asthma.

**Findings** Findings suggest key 'levers' to patient-centred care with children include: (1) engagement with children's expertise about their own lives: their personal and social experiences of their care, including how these are affected by their relative lack of power in some settings; (2) exploring children's understandings and preferences in terms of their physical sensations and day to day experiences; (3) willingness to find resources to engage with even the youngest children; (4) avoiding agebased assumptions about children's contributions to their care.

**Discussion** Action on the above 'levers' may present a range of challenges in healthcare settings not least because it represents a move away from medicine's historical focus on children's developing competencies to engage rather with children's social realities from the earliest ages.

## Introduction

The last 10 years have seen increased acknowledgement of the role of patient expertise in improving the quality of National Health Service (NHS) services (Department of Health 2000), alongside a growth in recognition of children as competent (Department of Health 2002), with the right to a voice in decision-making about his or her life (United Nations 1989) and expertise valuable to the development of effective services (Department of Children, Schools and Families & Department of Health 2009). Both the Children's and the Diabetes National Service Frameworks call for a child-centred approach to care (Department of Health 2001, 2004). However, young people with longterm illness report feeling marginalized in paediatric consultations (Young *et al.* 2003), and there is a gap in the evidence base about how patient-centred care with children is best achieved (Sanz 2003). Using type 1 diabetes and asthma as case studies, this review set out to synthesize findings of children's experiences of longterm illness and, from this, to identify levers and barriers to patient-centred care with children.

Patient-centredness has been understood as both a focus on the patient as a person, and the incorporation of power sharing between patient and clinician (Lewin *et al.* 2001). Subsequent analysis has identified two further dimensions: not only shared decision-making in the realm of one-to-one doctor–patient relations, but also the patient making decisions in the role of selfmanager of his or her illness outside the clinical setting, and further as evaluator of his or her experiences of NHS services (Coulter 2002). The work of Patricia Sloper and her team at York University has amply described the state of the evidence in this last sphere (Cavet & Sloper 2004; Heaton *et al.* 2008). Thus, using type 1 diabetes and asthma as case studies, the aim of this synthesis was to explore what may hinder and what may support the development of patient-centred care with children in terms of one-to-one doctor–patient relations and decision making about care.

A focus on insulin dependent type 1 diabetes was chosen because the relentless daily regimen of blood tests, injections and judgement calls on diet and exercise creates opportunities to explore harmony and conflict between children's wider priorities and the treatment regimen. Studies with children with asthma were also included in order to explore the generalizability of

findings across illnesses and because, like diabetes, the regimen intrudes into day to day life. Further, scoping searches carried out prior to the main review suggested a greater volume of relevant work in this area, in particular with minority ethnic populations, compared with other paediatric longterm illnesses. The poor health outcomes of people with minority ethnic backgrounds – relating to poverty and discrimination (Karlsen & Nazroo 2002) – make their experiences a priority for research at a time when a key task for health policymakers is to address health inequalities between different social groups (Acheson 1998). We know that those with disadvantaged or minority ethnic backgrounds tend to bear the highest burden of disease alongside the worst provision of health care (TudorHart 1971).

## Design

The review was designed as a synthesis of findings from studies of the experiences of children living with type 1 diabetes or asthma. Free text searches round the terms ‘asthma’, ‘diabet\$’ and child or related synonyms – with, where appropriate, qualitative filters (Petticrew & Roberts 2006) – were made across Medline, PsycINFO and CINAHL (1982–), Applied Social Science Index and Abstracts, Sociological Abstracts, International Bibliography of the Social Sciences (1981–), ChildData, and Dissertation Abstracts. Field experts and first authors of included studies were contacted for information about relevant studies, and bibliographies of included studies handsearched.

Qualitative approaches have been recognized as the best methods for gathering data on patients’ values and experiences (Sackett & Wennberg 1997). Commentators recommend research with young children comprise a range of face-to-face activities from ‘straightforward conversation’ to ‘task-centred’ activities such as drawing or taking photographs (Harden *et al.* 2000), used as a stimulus for discussion (O’Kane 2000; Alderson 2008). On this basis, it was decided to include only studies where (1) data collection incorporated an instrument with open-ended questions delivered face-to-face with participants to capture qualitative data; (2) data were analysed and reported qualitatively.

Previous work has suggested a gap in the evidence about the perspectives of younger children on their diabetes care (Brandt 1998; Greene 1999a; Grey 2000). To address this, studies were only included where the mean age of children in the sample (or if not known, median) was 10 years or younger.

The views and priorities of children with long-term illness about their health and illness have been shown to be different from those of their parents (Callery *et al.* 2003; Jutras *et al.* 2003). Commentators have suggested the importance of ensuring children, not their carers, are at the centre of social studies of childhood (Qvortrup 1994), and warned that children's perspectives can be obscured in studies with the whole family (Mayall 1996). Initial scoping found that in some studies the views of parents and children are elided (Horner 1992; Ambrose 1997; Buford 2001). In order to ensure the synthesis reflected children's perspectives (rather than those of their parents or siblings), only those studies were included where there was a clear and significant focus on the experiences of the child with type 1 diabetes or asthma, rather than those of the whole family: studies where children were granted 'conceptual autonomy' (Qvortrup 1994).

In order to gather literature on children's experiences within one generation (defined for the purpose of this work as 25 years) (Lucas *et al.* 2007), studies from 1980 onwards only were included. Studies were assessed for methodological quality using an instrument based on one developed to evaluate studies of children's views at the Institute of Education, University of London (Thomas *et al.* 2003) (see Table 1). Findings on the perspectives of children with diabetes or asthma were extracted, and managed in QSR\*Nudist. Data were synthesized using tools from Narrative Synthesis, which include exploration of the impact of individual researchers' understandings on their findings (Popay *et al.* 2006).

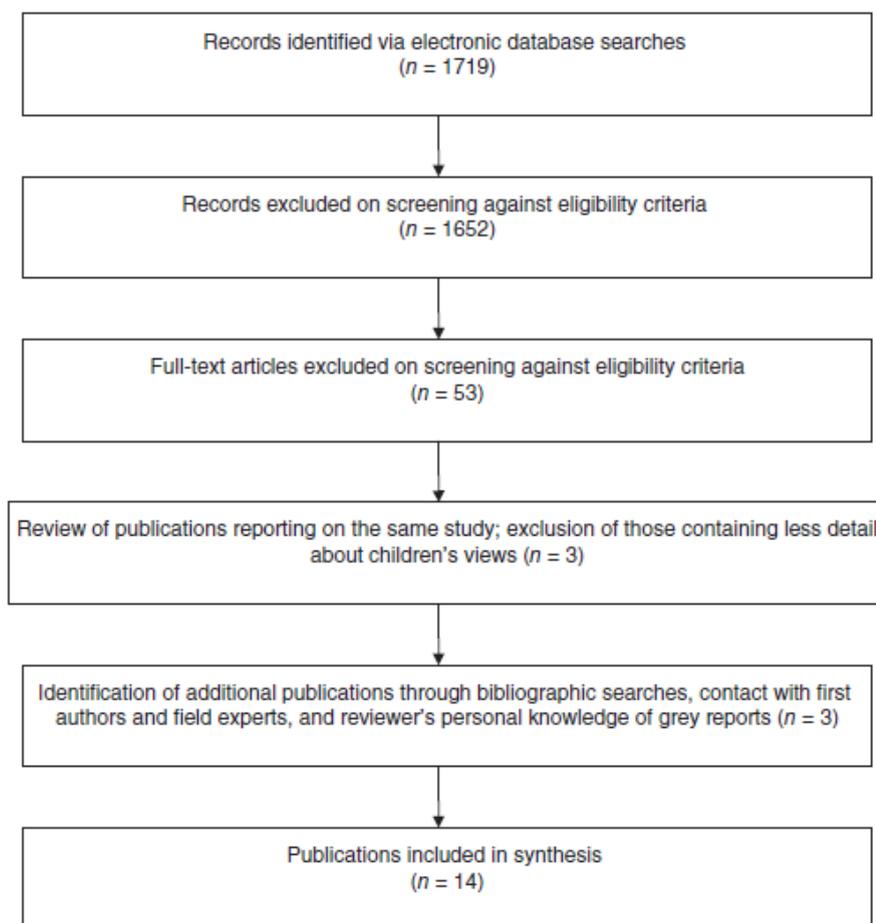
**Table 1.** Methods assessment framework

		Score	Comments
Quality of reporting			
1	Aims and objectives clearly reported		
2	Adequate description of the context for carrying out the research		
	Reasons for doing the study including review of relevant literature		
3	Adequate description of the sample		
	Description of sampling frame used		
	Indication of how participants selected from sampling frame eg purposefully sampled		
	Basic details about socio-demographics of participants including SES and ethnicity		
4	Adequate description of data collection methods		
	Description of procedures for collecting and recording data		
5	Adequate description of data analysis methods		
	Description of development of themes/categories		
	Description of allocation of data to codes and categories		
Establishing validity (rigorous employment of instruments) and reliability (accounting for variability in context/observers)			
6	Reliability of qualitative data collection methods		
	Description of main theoretical ideas informing study		
	Reflection on impact of person who carried out data collection		
	Reflection on impact of any changes in the context in which the study was undertaken		
	Reflection on impact of data collection methods		
7	Validity of qualitative data collection methods (relates to rigour of data generation)		
	Appropriate methods for recording data		
	Transcriptions made immediately after recording and/or double-checked for accuracy		
	Measures to help children express themselves freely eg reassurances of confidentiality/enjoyable activities		
	Questions piloted		
	Description of setting in order to inform potential for transferability		
8	Reliability of qualitative data analysis		
	Use of data management tools which facilitate within and across case analysis, using independent raters, identifying negative cases or illuminating diversity		
9	Validity of qualitative data analysis methods (relates to rigour of interpretation)		
	Triangulation of data from different sources		
	Demonstration of depth of analysis via thick description/use of contributor's terms		
	Demonstration of range of views via inclusion of vignettes appended with participant details		
	Respondent validation		
10	Extent to which findings are rooted in children's own perspectives		
	Use of appropriate data collection methods for helping children to express their views		
	Use of appropriate methods for ensuring the data analysis grounded in the views of children		
	Involved children in the design and conduct of the study		

Score: 1, poor attempt – no aspect addressed; 2, adequate attempt – one or more aspects addressed; 3, good attempt – majority of aspects addressed. SES, socio-economic status.

## Findings

A total of 1719 records were identified via electronic searches. In total, 1652 were excluded on screening against eligibility criteria. Sixty-seven full text papers were screened, of which 53 were excluded against eligibility criteria. A further three of these were excluded because they were reports of studies already included but which contained less detail about children's views. Hand-searching bibliographies of included papers identified one further relevant study (Dell Clark 2003). The author included two relevant unindexed and unpublished reports from her earlier fieldwork (Sutcliffe *et al.* 2004; Tyler 2009) (Fig. 1).



**Figure 1.** Strategy for selection of studies in synthesis.

The synthesis drew on 14 descriptive studies of participants' views and experiences ( $n = 426$ ), with 214 girls and 212 boys. Most authors recruited children from clinics (six), although several used support groups or camps (four) and schools (two); two authors did not report their sample frame. All used one to one or group discussion to gather children's views. Details of methods and/or findings are set out in Table 2. Most studies were USA based, with children with asthma (see Table 3).

**Table 2.** Summary of studies in synthesis

Study	Participants: settings, number, age, gender, socio-economic background, ethnicity, illness (authors' descriptors)	Summary of findings on children's experiences of illness and care
Walsh 1983	Minnesota and N Central Iowa; 61; 7–12 years; 30 girls, 31 boys; an even spread across range of SES; 52 Caucasian, 9 black; asthma – 29 moderate, 22 severe, 9 mild asthma	Some children described feeling isolated, being teased and experiencing differential treatment in the form of both restrictions and attention. Children could not draw a bio-medical model of the lungs and did not know the correct names for their medicines.
Zahorik 1990	NE Ohio; 26; 6–12 years; 15 girls, 11 boys; SES not reported; 6 black, 20 white; diabetes diagnosed at least 6 months before first interview	Children view their condition both as a disease and a series of management tasks. By successfully participating in self-care, children learn they can become responsible for their health.
Spezia 1991	Rural SE Missouri or S Illinois; 7; 9–12 years; 3 girls, 4 boys; middle income; 7 Caucasian; insulin-dependent diabetes diagnosed for 1 year or more	Self-care activities included knowing insulin dosages, drawing up/administering insulin, monitoring glucose levels, maintaining diet, exercising and assuming a degree of responsibility/decision-making.
Ireland 1997	UK; 10; 9–12 years; 5 girls and 5 boys; SES not reported; ethnicity not reported; asthma diagnosis for at least 1 year	Children described feeling different from their peers and ways in which they establish their own normality. Findings show that being 'normal' does have benefits although in some cases it also encourages the acceptance of suboptimal control.
Miller 1999	UK; 6; 7–12 years; 2 girls, 4 boys; SES not reported; ethnicity not reported; insulin-dependent diabetes	Children described confusion and disbelief on diagnosis; and felt management to be boring, time-consuming and intrusive. Being the same as others was very important; structures in school can make this hard to achieve.
Pradel <i>et al.</i> 2001	North Carolina; 32; 7–12 years; 12 girls, 20 boys; socially diverse; 15 black, 16 white, 1 native American; moderate to severe asthma	Children's competence in managing their illness and medications varied by age. All children perceived the benefits and non-monetary costs of asthma medicines, but lacked understanding of the categories and role of these.
Meng & McConnell 2002	USA; 28; 7–12 years; 11 girls, 17 boys; SES not reported; 15 African-American and 13 Caucasian; moderate to severe asthma	Children's decisions to medicate are guided by the presence of symptoms. They tend to overlook trigger avoidance and early warning signs.
Dell Clark 2003	Chicago urban and suburban areas; 46; mainly 5–8 years; 23 girls, 23 boys; diverse, but not inc many very poor (personal communication); approx. 4 Hispanic/African-American; approx. 42 white (personal communication); diabetes or severe asthma	Children understood their illness in terms of interventions and personally felt symptoms. They expressed fear of asthma and dislike of the intrusiveness of the diabetes regimen. Coping strategies included story-telling, role-reversal play, humour and ritual.
Koinis Mitchell 2003	Massachusetts; 31 at year 1, 28 at year 2; 7–10 years (at commencement of fieldwork); 16 girls, 15 boys; diverse, with 24 families on or below poverty threshold; 21 black, 1 white, 6 Hispanic, 1 American Indian, 2 multi-racial; asthma diagnosis	Children understood doing well in their care as following their treatment plan. They disliked the taste of medicines and having to avoid triggers. Some reported forgetting to take medicines when they were busy with friends.
Nabors <i>et al.</i> 2003	USA midwest; 105; 6–14 years; 60 girls, 45 boys; SES not reported; 6 African-American and 99 Caucasian; type 1 diabetes	Children felt supported at school although wanted extra flexibility from teachers in order to have access to medical supplies at all times – but in ways that minimize attention on them.
Boyle <i>et al.</i> 2004	South eastern USA; 19; 6–11 years; 10 girls, 9 boys; study conducted in low income area; African-American; asthma or 'breathing problems'	Children reported fear of not being able to breathe and described the limitations of living with asthma, particularly expressing remorse that physical activity is a trigger for asthma. They disliked the taste of medicines.
Sutcliffe <i>et al.</i> 2004	East and south-east London and a commuter town in south-east England; 24; 3–12 years; 10 girls, 14 boys; diverse (study conducted in both affluent and disadvantaged areas); 2 Asian, 3 black, 1 mixed-race, 18 white (reviewer's categories); type 1 diabetes	Some young children understand a great deal about daily diabetes care. They can be competent at making choices, managing difference and being 'normal'. Just 'getting on with life' is a key goal. They want routines that fit smoothly into their everyday life.
Rudestam <i>et al.</i> 2005	Providence, Rhode Island; 14; 8–12 years; 9 girls, 5 boys; poor; 6 Hispanic, 4 white, 4 African-American; moderate to severe asthma	Children experience asthma as an interruption in daily life, are more sensitive to places being 'dirty' and may be less likely to explore new or people-free places than their asthma-free peers.
Tyler 2009	East London; 17; 4–11 years; 8 girls, 9 boys; study undertaken in disadvantaged area; 6 Somali, 5 white British/English, 2 African, 2 Arabic, 1 Lithuanian, 1 Bengali-British; type 1 diabetes	Children's competent and active participation in their care at home contrasted with their passive role in clinic settings. They emphasized the interruption the regimen caused and disliked how this could threaten sameness with peers. Structures in schools could exacerbate this.

The range of paradigms associated with qualitative work, and philosophical assumptions underpinning these mean assessment of quality can be contested. However, the starting point for this review was that some methods are more appropriate than others for exploring people's subjective experiences, and their rigorous application is important in producing knowledge which, although provisional, is as accurate as possible at that time (Spencer *et al.* 2003). Studies were assessed using an instrument (see Table 1) based on one developed to evaluate studies of children's views (Thomas *et al.* 2003). Indicators for assessing the extent to which individual criteria were met were amended to include some of those described in the framework and commentary on the Cabinet Office's 'Framework for Assessing Qualitative Evaluations' (Spencer *et al.* 2003).

**Table 3.** Studies by location and illness

Studies of children with	USA	UK	Total
Asthma	6 (n= 185)	1 (n= 10)	7 (n= 195)
Diabetes	3 (n= 138)	3 (n= 47)	6 (n= 185)
Asthma or diabetes	1 (n= 46)	0	1 (n= 46)
Total	10 (n= 369)	4 (n= 57)	14 (n= 426)

**Table 4.** Methodological weaknesses for the purposes of this review

	Methodological weaknesses in relation to						Children's influence on conduct of study
	Sample description	Description of methods of data analysis	Reliability of data collection	Validity of data collection	Reliability of data analysis	Validity of data analysis	
Studies judged to be methodologically 'stronger' for the purposes of this review							
Sutcliffe <i>et al.</i> 2004							
Spezia 1991							
Tyler 2009							
Ireland 1997	•						
Rudestam <i>et al.</i> 2005					•		
Miller 1999	•				•		
Walsh 1983			•		•		
Studies judged to be methodologically 'weaker' for the purposes of this review							
Dell Clark 2003	•	•			•		
Koinis Mitchell 2003		•		•	•		•
Nabors <i>et al.</i> 2003	•		•	•			•
Pradel <i>et al.</i> 2001					•	•	•
Boyle <i>et al.</i> 2004			•			•	•
Meng & McConnell 2002	•		•			•	•
Zahorik 1990	•	•		•	•	•	•

The main methodological weaknesses of studies, for this review, lay in lack of demonstration of reliability and validity of data analysis, for example lack of 'thick' description, use of contributors'

terms, exploration of negative cases or tools to facilitate within and across case analysis (Walsh 1983; Zahorik 1990; Miller 1999; Pradel *et al.* 2001; Dell Clark 2003; Koinis Mitchell 2003; Nabors *et al.* 2003; Rudestam *et al.* 2005); and, in many cases, participants' inability to impact on the main course and conduct of the research (Zahorik 1990; Pradel *et al.* 2001; Meng & McConnell 2002; Koinis Mitchell 2003; Nabors *et al.* 2003; Boyle *et al.* 2004) (see Table 4). As the aim of the synthesis was to explore children's perspectives, with the exception of one study (Dell Clark 2003), those studies that facilitated children's influence on the course and conduct of the research were designated methodologically 'stronger' for the purposes of the review (Walsh 1983; Spezia 1991; Ireland 1997; Miller 1999; Sutcliffe *et al.* 2004; Rudestam *et al.* 2005; Tyler 2009) – and further because, with the exception of Dell Clark's work (Dell Clark 2003), these studies were also those with the smallest number of other methodological weaknesses. Dell Clark's study was not included within this group of 'stronger' work, because of the omission of a key aspect of the method: how data were analysed. It is worth noting that a marginal majority of studies designated 'stronger' were lengthy PhD or grey literature reports, while most of those deemed 'weaker' were papers published in journals. In some cases, it may have been that journal word limits prevented researchers from providing detail on all aspects of their methods. This draws attention to a particular challenge in reporting research undertaken using a 'qualitative' methodology and adds to the debate about the complexity of assessing quality in research which uses this approach. Six authors sampled children living with diabetes ( $n = 185$ ) (Zahorik 1990; Spezia 1991; Miller 1999; Nabors *et al.* 2003; Sutcliffe *et al.* 2004; Tyler 2008); seven sampled children living with asthma ( $n = 195$ ) (Walsh 1983; Ireland 1997; Pradel *et al.* 2001; Meng & McConnell 2002; Koinis Mitchell 2003; Boyle *et al.* 2004; Rudestam *et al.* 2005); and one included children with asthma or diabetes ( $n = 46$ ) (Dell Clark 2003). Studies of children's experiences of asthma were, with one exception (Ireland 1997), USA based, in most cases with samples of children predominately from minority ethnic backgrounds, perhaps related to concerns about the underdiagnosis and undertreatment of asthma in children with minority ethnic backgrounds (DuranTauleria *et al.* 1996; Sturdy *et al.* 1996). By contrast, studies of children's experiences of diabetes were both USA and UK based, and – with the exception of one UK project (Tyler 2009) – carried out with samples of children predominately from white (or unspecified) ethnic backgrounds, endorsing previous reviewers' findings that little is known about the experiences of children with minority backgrounds living with diabetes (Brandt 1998; Grey 2000).

Across all studies, most were carried out by authors with a nursing background. This was particularly true of earlier studies and may relate to the perception that concerns about patient

experience fall within the nurse's remit. Between 2001 and 2003, two papers were published by psychologists (Koinis Mitchell 2003; Nabors *et al.* 2003) and one by a pharmacist (Pradel *et al.* 2001), indicating some growing interest by other clinicians in patient day to day experiences and management of their care. After this, most studies are by authors with a social science background (Dell Clark 2003; Sutcliffe *et al.* 2004; Rudestam *et al.* 2005; Tyler 2009), perhaps reflecting the growing interest in children's experiences in that field (Prout 2002). An important observation is that it was only social scientists who had studied samples of children with a mean (or if not known, median) age of 7 years or younger. Those studies judged to be methodologically stronger for the purposes of this review were carried out by nurses (Walsh 1983; Spezia 1991; Ireland 1997; Miller 1999) or social scientists (Sutcliffe *et al.* 2004; Rudestam *et al.* 2005; Tyler 2009).

Few studies were explicit about underpinning assumptions and understandings of children and childhood. However, three papers by a psychologist, pharmacist and nurse were reported to be informed by theories from developmental psychology. These focused on children's cognitive abilities, seen to grow in relation to a series of identifiable stages (Walsh 1983; Pradel *et al.* 2001; Koinis Mitchell 2003). A fourth, by this author, a social scientist, was explicit about drawing on models from the 'new' social studies of childhood which focus on children 'as people important in their own right now', who lack economic and civic power compared with adults but have strong experiential knowledge about their lives (Tyler 2009).

Both levers and barriers to clinicians' engagement with children about their care emerged from the analysis. As these were often related, findings are set out in terms of what clinicians may do to facilitate patient-centred care with children.

### **Engaging with even the youngest children**

Less than half of studies included children under the age of 7 (Dell Clark 2003; Nabors *et al.* 2003; Boyle *et al.* 2004; Sutcliffe *et al.* 2004; Tyler 2009) and only two of these focused in detail on children's own responsibilities for care (Sutcliffe *et al.* 2004; Tyler 2009). Yet, the two – methodologically strong – studies, both by social scientists, that did consider younger children's

responsibilities found children to have high levels of involvement in and understandings of their illness at very young ages. Some children with diabetes at 4 years were reported to actively monitor their diet, interpret physical symptoms, know the times for, and carry out their own blood tests and insulin injections and explain their illness to others (Sutcliffe *et al.* 2004; Tyler 2009).

This suggests that where children's views are sought, the views of younger children may be excluded. Where they are included, there may be a tendency to focus on preferences and experiences, over their responsibilities and contributions. This chimes with findings from the one study that included observations of children in clinical settings and found younger children excluded from discussion of their condition with clinicians (Tyler 2009). Researchers who engaged with younger children used a range of methods to support children in describing their experiences. These included meeting with them in comfortable nonthreatening environments, centring questions around subjects familiar to children, especially their day to day lives and providing them with opportunities to use toys or props to demonstrate or role play their experiences, or pens to draw them (Dell Clark 2003; Nabors *et al.* 2003; Boyle *et al.* 2004; Sutcliffe *et al.* 2004; Tyler 2009).

### **Exploring children's preferences and understandings in terms of their physical sensations and day to day experiences of care**

Three authors of studies informed by theories focusing on children's cognitive abilities, and judged methodologically weaker for the purposes of this review, expressed concern that children did not know the 'correct' names of their medicines, nor could they draw an adequate biomedical diagram of their lungs (Walsh 1983; Pradel *et al.* 2001; Koinis Mitchell 2003). Other authors of studies, mainly gauged to have had fewer methodological weaknesses in the context of this review, found that while some children had begun to internalize biomedical models of their illness and body, most had strong understandings based in their bodily sensations and day to day experiences of their illness and care (Zahorik 1990; Dell Clark 2003; Sutcliffe *et al.* 2004; Rudestam *et al.* 2005; Tyler 2009). Rather than naming an insulin cartridge as such, one 6yearold child described it in terms of his experience of its use – 'You have to put (the cartridge) in the (injection pen) if the other one's finished'. Children routinely referred to their experience of hypoglycaemia in experiential rather than biological terms, describing it as 'feeling

shaky' or even 'my shake' (Tyler 2009). This suggests the importance of using children's physical sensations and daily routines as a starting point for engagement, rather than their understanding of biomedical models.

While children described physical discomfort arising from their illness or regimen (Walsh 1983; Zahorik 1990; Ireland 1997; Miller 1999; Pradel *et al.* 2001; Meng & McConnell 2002; Dell Clark 2003; Boyle *et al.* 2004; Rudestam *et al.* 2005; Tyler 2009), their accounts, across both illnesses – and across both methodologically stronger and weaker studies – also highlighted the restrictions and interruptions which their illness and care impose on their lives: the diabetes diet and its implications for day to day social life; the relentless, intrusive regimen of 'pricks' (both blood tests and injections); not being able to participate in sleepovers at friends' houses because of needing injections; having to avoid asthma triggers and hence limited time outdoors, with friends, playing sport or access to pets (Walsh 1983; Zahorik 1990; Spezia 1991; Ireland 1997; Miller 1999; Pradel *et al.* 2001; Meng & McConnell 2002; Dell Clark 2003; Koinis Mitchell 2003; Boyle *et al.* 2004; Sutcliffe *et al.* 2004; Rudestam *et al.* 2005). In the face of these disruptions, children described how important it was to them to maintain their sense of 'sameness' with peers (Zahorik 1990; Miller 1999; Sutcliffe *et al.* 2004; Tyler 2009). Some reported prioritizing a desire to minimize interruption and maintain their social identity over following the regimen. For children with asthma, this meant sometimes not taking medicines or ignoring advice to avoid triggers (Koinis Mitchell 2003) and, instead, using rescue medicines to treat symptoms (Ireland 1997; Meng & McConnell 2002; Rudestam *et al.* 2005). For children with diabetes, this could mean skipping injections or ignoring advice about diet and exercise (Zahorik 1990; Tyler 2009). Interestingly, in the absence of any data on children's views of why they do not follow advice about avoiding asthma triggers, one author of a study based on a theory of childhood focusing on children's cognitive abilities, assumed children in her study did not mention avoiding triggers because of 'a lack of *knowledge* of appropriate avoidance' (my italics) (Pradel *et al.* 2001). This was despite the fact that children in his or her study showed a good knowledge of triggers. This suggests children's decision-making about their care is likely to be as influenced by their day to day personal and social experiences as by their understandings and the latter is therefore an important area for exploration.

## **Engaging with how children's experiences of care are affected by their lack of power compared with adults**

Studies across the two illnesses described difficulties some children experienced in managing their illness because of their relative lack of control over their lives compared with adults. Children worried about lack of access to medical supplies in schools, or felt that school systems for managing their care unnecessarily threatened their 'sameness' with peers. Across both methodologically weaker and stronger studies, these concerns seemed to influence children's decision-making about their care, and sometimes led to their ignoring their regimen (Ireland 1997; Miller 1999; Meng & McConnell 2002; Nabors *et al.* 2003; Sutcliffe *et al.* 2004; Tyler 2009). In one study children reported parents ignoring their warnings that they were experiencing symptoms of hypoglycaemia, believing instead these were children's bids for extra food (Tyler 2009).

That children's perspectives are unique in this regard, and that parents and carers will not have had direct experience of these, reiterates the importance of ensuring engagement with children in their own right, avoiding their views being subsumed within those of the wider family.

## **Avoiding agebased assumptions about children's contribution to their care**

Findings from two studies of children with asthma informed by theories focusing on children's cognitive abilities at certain ages, and with methodological weaknesses relating to the reliability of their data analysis, suggested that older children who treat their condition autonomously use a wider range of techniques than younger children who tend towards less autonomous care (Walsh 1983; Pradel *et al.* 2001). While one diabetes study also found that broadly speaking there is an increase in children's responsibilities for their health care in line with age, possibly as a result of adult expectations (Tyler 2009), findings from this and another diabetes study provided a more nuanced picture. These methodologically stronger studies indicated that children's responsibilities at given ages vary considerably across families. Most children could not do their own insulin injections at 4 years; yet, there were exceptions to this (Sutcliffe *et al.* 2004). Some at this age actively monitored their diet (Sutcliffe *et al.* 2004) while others relied on parents to enforce this (Tyler 2009). Some children at 6 years accepted their thrice daily injections, while others actively resisted (Tyler 2009). Both found that in some families apparently

experiencing high levels of socioeconomic stress children reported particular difficulties in accommodating their illness and regimen (Sutcliffe *et al.* 2004; Tyler 2009).

Further, methodologically strong studies with children with diabetes suggested that adult/child shifts in divisions of responsibility for care over time did not take place linearly in direct relation to competence or age, but rather cyclically in relation to a wider range of factors (Sutcliffe *et al.* 2004; Tyler 2009). Children described taking greater responsibility for aspects of their care, such as doing insulin injections for a while, then relinquishing this for a time, and then take greater responsibility later.. They reported assumption of responsibility to relate not solely to competence but also to issues like convenience and interruption. For example, glucometers take a short time to provide a reading after submission of the blood sample. Children who could read and understand their glucometer feedback reported that they did not wait for this but rather left the task of reading their level to parents in order to minimize the interruption to their life caused by the thrice-daily tests (Tyler 2009). Others who had become adept in doing their insulin injections reported that at rushed times of the day they still preferred carers to do the injection (Zahorik 1990; Tyler 2009).

## **Discussion**

Action on the 'levers' to patient-centred care outlined above is likely to present a range of challenges in care for children with long-term illness. The first of these relates the extra time and resources involving in seeking out younger children's views. Children under the age of 10 are generally excluded from discussions of their illness with clinicians (Tates & Meeuwesen 2001). In discussions with clinical colleagues as part of knowledge exchange work from this synthesis (Tyler 2008), the author found that the extra time required to engage with younger children was cited as a major barrier to hearing from them about their experiences of care. That inclusion of younger children's experiences in their care planning is considered a luxury we can ill afford in a time of austerity only serves to emphasize findings from the synthesis about the extent to which children's lack of power in some settings compared with adults impacts on their lives as much as their developing capabilities.

Second, the rationale for greater lay involvement in health services has been

acknowledgement of the importance of patient expertise in designing and delivering good services (Department of Health 2000) – including when the patient is a child (Department of Health 2002). It is understandings of children's social realities that is key in this, as explored in the many social studies with children undertaken since the 1980s, now broadly known as the 'new social studies of childhood' (Prout & James 1997; Prout 2001). These took as their starting point a move away from a focus on children's cognitive development, in relation to an adult 'gold standard' in favour of a focus on what children can do. This is very different from the ways in which children are routinely conceptualized in medicine where developmentalist models focus on children's developing competencies and the biology related to this over children's social and environmental experiences (Greene 1999b; Mayall 2004).

Finally, social studies with children have drawn attention to the importance of trying to address the power imbalance between adult enquirers and child participants when exploring children's views and experiences. This presents a particular challenge in health settings where the difference in status is likely to be particularly stark: as other commentators have observed, children are doubly minor, both as children and as patients (Tates & Meeuwesen 2001).

In this review, the author assesses and synthesizes findings from her own primary research. The rationale for carrying out a synthesis instead of another primary study was that it facilitated exploration of researchers' differing attitudes to their subject matter (investigator triangulation) (Popay *et al.* 2006), and enabled findings to be drawn from a much larger sample than would have been possible otherwise. However, the author was concerned that her intimate knowledge of findings from primary studies which she had worked on may have heightened their prominence in the subsequent synthesis. A repeat of the synthesis by an 'external' researcher would be one way of beginning to explore this, in the context of our existing understanding that synthesis of 'qualitative' data is always to some extent provisional: different reviewers identify different themes from the same data, and the same reviewer does not produce the same set of themes on the same data at two different points in time (Popay *et al.* 2006).

### **Key messages**

Findings suggest 'levers' to patient-centred care with children are

- Engagement with children's expertise about their own lives: their personal and social experiences of their care, including how these are affected by their relative lack of power in some settings.
- Exploring children's understandings and preferences in terms of their physical sensations and day to day experiences.
- Willingness to find resources to engage with even the youngest children.
- Avoiding age- based assumptions about children's contributions to their care.

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## References

- Acheson, D. (1998) *Independent Inquiry into Inequalities in Health Report*. TSO, London, UK.
- Alderson, P. (2008) *Young Children's Rights: Exploring Beliefs, Principles and Practice*. Jessica Kingsley, London, UK.
- Ambrose, H. J. (1997) *Family Meaning among Mexican Americans Following the Diagnosis of Juvenile Diabetes*. PhD. St Mary's University, San Antonio, TX, USA.
- Boyle, J. S., Baker, R. R. & Kemp, V. H. (2004) Schoolbased asthma: a study in an African American elementary school. *Journal of Transcultural Nursing*, 15, 195–206.
- Brandt, P. (1998) Childhood diabetes: behavioural research. *Annual Review of Nursing Research*, 16, 63–82.
- Buford, T. A. (2001) *Transfer of Responsibility for Asthma Self Management from Parents to Their School Age Children*. PhD. University of Missouri, Columbia, MO, USA.

- Callery, P., Milnes, L., Verduyn, C. & Couriel, J. (2003) Qualitative study of young people and parents' beliefs about childhood asthma. *British Journal of General Practice*, 53, 185–190.
- Cavet, J. & Sloper, P. (2004) The participation of children and young people in decisions about UK service development. *Child: Care Health and Development*, 30, 613–621.
- Coulter, A. (2002) *The Autonomous Patient: Ending Paternalism in Medical Care*. TSO, London, UK.
- Dell Clark, C. (2003) *In Sickness and in Play: Children Coping with Chronic Illness*. Rutgers University Press, Piscataway, NJ, USA.
- Department of Children, Schools and Families & Department of Health (2009) *Healthy Lives, Brighter Futures: The Strategy for Children and Young People's Health*. Department of Health, London, UK.
- Department of Health (2000) *NHS Plan: A Plan for Investment, A Plan for Reform*. Department of Health, London, UK.
- Department of Health (2001) *National Service Framework for Diabetes Standards*. Department of Health, London, UK.
- Department of Health (2002) *Listening, Hearing and Responding – Department of Health Action Plan: Core Principles for the Involvement of Children and Young People*. Department of Health, London, UK.
- Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*. Department of Health, London, UK.
- DuranTauleria, E., Rona, R. J., Chinn, S. & Burney, P. (1996) Influence of ethnic group on asthma treatment in children in 1990–1: national cross sectional study. *British Medical Journal*, 313, 148–152.
- Greene, S. (1999a) Diabetes in the preschool child. *Diabetes Nutrition & Metabolism*, 12, 96–101.
- Greene, S. (1999b) 'Child development': old themes, new directions. In: *Making Sense of Social Development* (eds M. Woodhead, D. Faulkner & K. Littleton), Routledge in association with the Open University, London, UK and New York, NY, USA.
- Grey, M. (2000) Interventions for children with diabetes and their families. *Annual Review of Nursing Research*, 18, 149–170.
- Harden, J., Scott, S., BackettMilburn, K. & Jackson, S. (2000) Can't talk, won't talk?: Methodological issues in researching children. *Sociological Research Online*, 5.
- Heaton, J., Sloper, P. & Clarke, S. (2008) Access to and use of NHS Patient Advice and Liaison Service (PALS): the views of children, young people, parents and PALS staff. *Child Care Health*

- and Development*, 34, 145–151.
- Horner, S. D. (1992) *Catching the Asthma: Family Caring about SchoolAged Asthmatic Children*. PhD. Medical College of Georgia, Augusta, GA, USA.
- Ireland, L. M. (1997) Children's perceptions of asthma: establishing normality. *British Journal of Nursing*, 6, 1059–1064.
- Jutras, S., Morin, P., Proulx, R., Claude Vinay, M., Roy, E. & Routhier, L. (2003) Conceptions of wellness in families with a diabetic child. *Journal of Health Psychology*, 8, 573–586.
- Karlsen, N. & Nazroo, J. Y. (2002) Agency and structure: the impact of ethnic identity and racism on the health of ethnic minority people. *Sociology of Health and Illness*, 24, 1–20.
- Koinis Mitchell, D. (2003) *Building Roads to Resiliency for Urban Children with Asthma: Linking Research with Intervention*. PhD. University of Massachusetts, Boston, MA, USA.
- Lewin, S. A., Skea, Z. C., Entwistle, V., Zwarenstein, M. & Dick, J. (2001) *Interventions for providers to promote a patient-centred approach in clinical consultations (review)*. *Cochrane Database of Systematic Reviews*, Issue 4. Art. No. CD003267. DOI: 10.1002/14651858.CD003267.
- Lucas, P. J., Arai, L., Baird, J., Kleijnen, J., Law, C. M. & Roberts, H. M. (2007) A systematic review of lay views about infant size and growth. *Archives of Disease in Childhood*, 92, 120–127.
- Mayall, B. (1996) *Children, Health and the Social Order*. OpenUniversity Press, Buckingham, UK.
- Mayall, B. (2004) Sociologies of childhood. *Developments in Sociology*, 20, 37–56.
- Meng, A. & McConnell, S. (2002) Decision-making in children with asthma and their parents. *Journal of the American Academy of Nurse Practitioners*, 14, 363–371.
- Miller, S. (1999) Hearing from children who have diabetes. *Journal of Child Health Care*, 3, 5–12.
- Nabors, L., Lehmkuhl, H., Christos, N. & Andreone, T. L. (2003) Children with diabetes: perceptions of supports for selfmanagement at school. *Journal of School Health*, 73, 216–221.
- O'Kane, C. (2000) The development of participatory techniques facilitating children's views about decisions which affect them. In: *Research with Children: Perspectives and Practices* (eds P.Christensen & A. James), pp. 136–159. Routledge/Falmer, London, UK.
- Petticrew, M. & Roberts, H. (2006) *Systematic Reviews in the Social Sciences: A Practical Guide*. Blackwell Publishing, Oxford, UK.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M. & Britten, N. (2006)

*Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. A Product from the ESRC Methods Programme.* Lancaster University, Lancaster, UK.

Pradel, F. G., Hartzema, A. G. & Bush, P. J. (2001) Asthma selfmanagement: the perspective of children. *Patient Education & Counselling*, 45, 199–209.

Prout, A. (2001) Representing children: reflections on the Children 5–16 Programme. *Children & Society*, 15, 193–201.

Prout, A. (2002) Researching children as social actors: an introduction to the Children 5–16 Research Programme. *Children & Society*, 16, 67–76.

Prout, A. & James, A. (1997) A new paradigm for the sociology of childhood? Provenance, promise and problems. In: *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* (eds A. James & A. Prout), pp. 7–33. Falmer Press, London, UK.

Qvortrup, J. (1994) Childhood matters: an introduction. In: *Childhood Matters: Social Theory, Practice and Politics* (ed. J. Qvortrup, et al.), pp. 1–23. Avebury, Aldershot, UK.

Rudestam, K., Brown, P., Zarcadoolas, C. & Mansell, C. (2005) Children's asthma experience and the importance of place. *Journal for the Social Study of Health, Illness and Medicine*, 8, 423–444.

Sackett, D. L. & Wennberg, J. E. (1997) Choosing the best research design for each question. *British Medical Journal*, 315, 1636.

Sanz, E. J. (2003) Concordance and children's use of medicines. *British Medical Journal*, 327, 858–860.

Spencer, L., Ritchie, J., Lewis, J., Dillon, L. & National Centre for Social Research (2003) *Quality in Qualitative Evaluation: A Framework for Assessing the Research Evidence.* Cabinet Office, London, UK.

Spezia, M. A. (1991) *Family Responses and Care Activities in SchoolAged Children with Diabetes.* PhD. University of Alabama, Birmingham, AL, USA.

Sturdy, P., Nash, J., Carter, Y. & Griffiths, C. (1996) Letters: study in London confirms influence of ethnic group on treatment for asthma. *British Medical Journal*, 313, 1260.

Sutcliffe, K., Alderson, P. & Curtis, K. (2004) *Children As Partners in Their Diabetes Care: An Exploratory Research Study.* Social Science Research Unit, Institute of Education, University of London, London, UK.

Tates, K. & Meeuwesen, L. (2001) Doctorpatientchild communication: a (re)view of the

- literature. *Social Science and Medicine*, 52, 839–851.
- Thomas, J., Sutcliffe, K., Harden, A., Oakley, A., Oliver, S., Rees, R., Brunton, G. & Kavanagh, J. (2003) *Children and Healthy Eating: A Systematic Review of Barriers and Facilitators*. EppiCentre, Social Science Research Unit, Institute of Education, University of London, London, UK.
- TudorHart, J. (1971) The inverse care law. *Lancet*, 1, 405–412.
- Tyler, K. (2008) *Findings from Knowledge Exchange Activity Arising from A Study of the Contribution of SchoolAge Children's Views to Their Care*. City University, London, UK.
- Tyler, K. (2009) *Levers and Barriers to Patient-centred Care with SchoolAge Children: Type 1 Diabetes As A Case Study*. PhD. City University, London, UK.
- United Nations (1989) *Convention of the Rights of the Child*. UN, Geneva, Switzerland.
- Walsh, M. (1983) *The Experience of Asthma in Childhood*. PhD. University of Illinois at Chicago, Health Sciences Center, Chicago, IL, USA.
- Young, B., DixonWoods, M., Windridge, K. C. & Heney, D. (2003) Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *British Medical Journal*, 326, 305–309.
- Zahorik, P. M. (1990) *Juvenile Diabetes: A Study of Children's Perceptions of Their Illness*. PhD. Case Western Reserve University, Cleveland, OH, USA.