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Levers and barriers to patient-centred care with school-age children living with long-term illness in multi-cultural settings: Type 1 diabetes as a case study

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Katherine Tyler, May 2008

Abstract

In response to the Children's National Service Framework and NHS modernisation agenda on the involvement of stakeholders, and to an important problem for children, families and clinicians in the local health economy, this study aims to understand and identify levers and barriers to patient-centred care in multi-cultural settings for children living with long-term illness. I carried out qualitative work with 17 children aged between 4 and 11 years-old being treated for type 1 diabetes in two clinics in East London. I synthesised findings from this with findings from 13 other studies of the experiences of school-age children living with type 1 diabetes or – in order to explore the generalisability of diabetes studies – children living with asthma.

Findings suggest that, across illnesses and ethnicities, although school-age children share their health care, usually with mothers, their care is affected by their own experiences and understandings of the illness and regimen, the relative disruption these experiences cause across physical, social and emotional spheres, and the extent that these are exacerbated by their low social status - compounded especially in multi-cultural settings, by structures at meso- and macro-levels. Disruption to precious 'free' time and social identity are a particular concern for children.

Key characteristics of patient-centred care are, therefore, engagement with school-age children's day-to-day experiences and understandings of their illness and care, and recognition of the extent to which decision-making is shared between children and adults in domestic settings. Barriers to the achievement of these include current medical and generational hierarchies, in particular their impact in the clinical encounter, and views of children which emphasise their developing competencies as adults-in-the-making as opposed to people in their own right. Unless these are tackled, technologies to ensure children have greater opportunity to set the agenda in clinical environments could become merely instruments for coercion and manipulation. To avoid this we need to disseminate new ways of thinking about children and childhood and better understandings of children's experiences of their health and health care. Particularly important are models of childhood from the social studies of children; and the 'evidence-based' paradigm where the key role of 'users' in the development of good services is recognised.

Findings have implications for our understandings of not only generational inequality on children's experiences of long-term illness and care; but also of how adult views of children as 'becomings' make it difficult for adults to relinquish control over children's lives. Findings also include reflections on new approaches to the synthesis of qualitative data, and raise issues around the distinction of 'process' from 'findings' data, and undertaking qualitative synthesis as a sole researcher.

Chapter 1: Introduction

In this introductory chapter I first set out the aims and objectives of the work, my rationale in undertaking it, and my thinking about children and childhood within this. The second part of the chapter describes the policy background and identifies my particular area of interest within this. I end with an overview of clinical information on type 1 diabetes and an explanation of why I chose children's experiences of this illness as a case study for this work.

1.1 Aims and objectives

In 2000, the NHS Plan set out that health care services should be designed and delivered around the needs of the patient (Department of Health 2000). This study aims to understand and identify levers and barriers to patient-centred care in multi-cultural settings with children living with long-term illness.

The objectives are:

- Using type 1 diabetes as a case study, to use methods from systematic review and ethnography to gather data on the experiences, understandings, practices and preferences of children in managing their illness alongside families and health professionals

- From this to identify:

  i) key aspects of patient-centred care for children

  ii) levers and barriers to its achievement

1.2 Rationale

I carried out this work at a time where a key task for health policy makers has been to address health inequalities between different social groups (Acheson 1998), such as those at different points on the socio-economic spectrum: not just the 'health gap' between those at the top and the bottom, but the gradient which relates health to socio-economic position across the population (Graham 2006). While much of what we know to be important in tackling health inequalities relates to education, employment, social welfare, and wider fiscal interventions, we do know particular inequalities relate to provision of health care: specifically that those with the highest burden of disease - those with disadvantaged or minority ethnic backgrounds - also tend to be those with worst provision of health care (Tudor-Hart 1971) – so that research studies, such as this one, which seek to improve health care provision to these groups may also contribute to building the evidence base for tackling health inequalities.

When I describe contributing to the 'evidence base' for health inequalities, I am referring to that movement within health and social care that is identified with the idea that decision-making about service provision should be made in light of 'the conscientious, explicit, and judicious use of current best (research) evidence' (Sackett & Wennberg 1997). The importance of extensive searching and appraisal to identify what is currently 'best' is central. It could be argued that in the past, a focus on effectiveness and issues of quality within this – in particular, how randomisation reduces bias in studies of effectiveness (Chalmers 2003) – has crowded out attention to the range of other kinds of evidence needed, and, particularly importantly, how to ensure quality in these. However, it is now increasingly recognised that we do need other kinds of good quality evidence: to develop effective interventions, to develop good evaluations, to understand why interventions do or do not work, to describe interventions and their implementation, to inform decisions about transferability, and to evaluate interventions in practice settings (Rychetnik et al. 2004; Petticrew & Roberts 2003;

Greenhalgh 2002) and a vital aspect of good intervention development and evaluation is attention to user satisfaction and acceptability. Good understandings of stakeholder perspectives – as sought in this study - are essential to designing better services (Roberts et al. 2004; Sackett & Wennberg 1997).

We know that better services for children are important because of the impact of early health on long-term adult health (Graham & Power 2004). However, I am also undertaking this study from a children's rights point of view: that children have a right to good health care as people now, not just as future adults (United Nations 1989). Further, Article 12 of the United Nations Convention on the Rights of the Child (United Nations 1989) – to which the UK was a signatory in 1991 – states the right of children to freely express their views on decisions affecting their lives and to have these taken into account subject to their age and maturity. The implication of this in relation to provision of services, specifically health services, is that children receiving services have a right to a say about service design and delivery.

So, my motivation in this work is both a belief that children have a right to have a say about their lives, and a commitment to the idea that what they say is of fundamental importance in sensible decision-making in policy and practice to address inequalities in health care provision. To some extent this challenges the idea within Article 12 that children's views should only be taken into account according to their age and maturity, since provided methods for exploring children's views are valid, then the views of all children are relevant to the design of effective services. Further, perhaps a coupling of a rights-based and an evidence based approach is useful to add impetus to the drive to 'close the implementation loop' within the phenomenon increasingly apparent over the last ten years: children's views elicited but not acted upon (Curtis et al. 2004a; Kirby & Bryson 2002; Morrow 2000; Roberts 2000).

1.3 Thinking about children

The rationale I have described for undertaking this work rests on certain ways of seeing children and childhood, drawn principally from sociology and anthropology, which I want to make explicit. From the beginning up to and including the middle part of the twentieth century, sociological thinking about children was mostly concerned with the notion of a passive and linear process of socialisation for adulthood (Prout & James 1997) whereby - with adulthood as the benchmark - children were cast as vulnerable, dependent and incompetent, economic non-contributors with little social responsibility and no voice of their own (Hardman 1973). Within psychology there was a particular interest in the processes of children's biological and cognitive development which largely eclipsed consideration of the impact of their social experiences. This tended, first, to conflate children's differing experiences of their childhoods and, secondly, to shift attention away from current competencies onto shortcomings in relation to future adulthood (Qvortrup 2005; Prout & James 1997; Qvortrup 1994;). With a few notable exceptions, for example Pinchbeck and Hewit's extensive account of 'Children in English Society' (Pinchbeck & Hewitt 1973), the focus tended to be on children as future adults rather than people in their own right (Lee 2001; Qvortrup 1994).

However, work by historians in the 1960s began to highlight the variability in ways of thinking about children and childhood, and also of different children's experiences of childhood (Hendrick 2001; Qvortrup 1994). In the 1990s the Economic and Social Research Council (ESRC) funded a major research initiative which focused on the perspectives of children in their worlds now, rather than as adults in the making (Prout 2002). This challenged the notion of children as 'unreliable witnesses about their own lives' and revealed new aspects of situations previously only considered from an adult point of view (Prout 2006; Qvortrup 1994). In opposition to previous ideas about children as passive recipients of socialisation (Prout 2006), a central tenet of this and subsequent work was recognition of children's capacity to make decisions and act on them in ways that impact on their own lives and those of people around them (Mayall 2002; Prout & James 1997; Mayall 1996; Qvortrup 1994). It is these ideas that have fed understandings that the things children do and say are important in their own right, and should not be conflated with those of their family as a whole (Mayall 1996; Oakley 1994) - and that have underpinned a rise in interest in children's participation in public decision making. Bearing this in mind it is instructive that the National Service Framework for Children (NSF) which sets standards for health care with children is combined with the NSF for maternity services for pregnant women (Department of Health 2004b).

As well as identifying children's 'agency' in their own lives, these new ways of thinking about children and childhood highlighted the inequality between the social status of adults and children, in particular children's lack of economic and civic power (Harden et al. 2000; Christensen 1998; Alderson & Goodey 1996) and how, especially 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 (Mayall 2002; Lee 2001; Mayall 1994a; Qvortrup 1994). Jens Qvortrup has suggested that adult drives to protect children may be (unwittingly) as much about desires to protect the social order as about children's vulnerability (Qvortrup 1994); and Alan Prout and Allison James have described how these ways of seeing children can act as 'self-fulfilling prophecies', in that, once in place, it is very difficult for anyone – teacher, parent or child – to see children in any other way (Prout & James 1997).

To try to break from this, researchers within the 'new' studies of childhood have emphasised their view of children as people important in their own right now, not just as future adults: people who did not have to be "approached from an assumed shortfall of competence, reason or significance" (James et al. 1998, p 207). This means seeing children's competencies as different, rather than 'less' than adult competencies (James et al. 1998) and as relating to how children's experiences and understandings of the world differ from adults' experiences and understandings (Punch 2002; O'Kane 2000; Thomas & O'Kane 1998). Further, using the concept of 'conceptual autonomy' (Thorne 1986), Jens Qvortrup has asserted the importance of ensuring that social studies of children really do put children, not their carers, at the centre (Qvortrup 1994). Commentators have also recommended a move away from thinking about the fixed categories of 'child' versus 'adult', and instead a focus on the idea of "generation" (Prout 2006; Mayall 2002) since this avoids the essentialism that may be associated with ideas of 'the child' or 'childhood' and more readily facilitates opportunities for broader and more complex understandings of children's lives that recognise differences within as well as between groups, (for example between children of different ages), and include interaction with other social variables such as ethnicity, class and gender.

So, in undertaking this study, my assumption is that children are a heterogeneous group of people important in their own right, who have an impact on their own and the lives of those around them, and can be reliable sources of information on their own lives; yet who have the potential to be marginalised, ironically, by adult concern about their vulnerability. An important theme for this work may be to try to 'delineate' this vulnerability in order to identify aspects of its scope and limits (Qvortrup 1994).

1.4 Policy background

I have separated out my personal rationale in doing this work, described earlier, from the policy background which I outline here, because although there are overlaps between the two, I want to describe the policy background, particularly in health, in some detail in order to identify my specific area of interest within this.

This study relates to three key areas of policy-making. The first is around equality, and addressing discrimination, particularly in relation to race. In response to findings of institutional racism in the report into the murder of

Stephen Lawrence (Macpherson 1999), the Race Relations (Amendment) Act 2000 (The Race Relations (Amendment) Act 2000) placed a duty on public authorities to eliminate unlawful discrimination, and promote equality of opportunity and good relations between people from different racial backgrounds – not only amongst employees, but also amongst those to whom services are provided. The NHS, as much as any other public body, is responsible for ensuring its services are accessible, and meet the needs of patients, regardless of their ethnic background. This duty is reiterated in proposals arising out of a recent government review of anti-discriminatory legislation (Department for Education and Skills et al. 2007).

The second key area of policy-making, around children's rights and participation, was embodied in law when the UK signed up the United Nations Convention on the Rights of the Child in 1989 (United Nations 1989). This gave children some voice in decision-making across different aspects of their lives. That same year, the Children Act 1989 confirmed that decisions made in court about a child's future must take into account the ascertainable 'wishes and feelings' of children – again relative to age and understanding. Over the next few years, publications by the Children and Young People's Unit (Children and Young People's Unit 2001), and then by the Department of Health (Department of Health 2002) set out the Government's commitment to increasing children's 'involvement in the design and provision of government policies and services' (Children and Young People's Unit 2001, p 1); and, specifically, that 'children with illness, particularly those with long-term conditions, must be cared for… in the light of their own views and decision-making' (Department of Health 2002, p 4).

The guidance for applications to the Government's new Children's Fund in 2001 included a specific stipulation that plans involve children in an on-going dialogue on service development (Children's Fund 2001). Two years later, in the Inquiry into the death of Victoria Climbié (Laming 2003), Lord Laming criticised professionals' deference to the needs of Victoria's carers, at the expense of the needs of Victoria herself, and recommended the establishment of a Children's Commissioner for England to promote awareness of the views and interests of children. This was instituted in the following year as part of the Children Act 2004.

The final key area of policy agenda concerns the role of patients in having a voice in decision-making about their health and health service development. The overview of this in the following paragraphs sets out how the rationale for recent drives for lay involvement in health care has tended to relate to acknowledgement of the importance of patient expertise in designing and delivering good services (Department of Health 2000). However, in relation to children's services, lay involvement has either had an explicitly rights based rationale (United Nations 1989); or, with the exception of the Department of Health's 'Core principles for the involvement of children and young people' (Department of Health 2002), where there are statements about children's expertise, these have tended to be more provisional (Children and Young People's Unit 2001) or absent altogether (Department of Health 2004b; Children's Fund 2001). It is debateable as to whether or not this reflects a discomfort with public support of the idea of children as reliable witnesses to their own lives, and hence a view of children as less trustworthy sources of information for developing good services than adults.

Lay involvement in health service design and delivery has come to be known as 'patient-centred' care. This idea was first posited in the 1950's to designate something similar, but rather different: a focus on the patient as opposed to the illness (Lewin et al. 2001). Later commentators used it simply to describe the clinician's attempt to see the world, and the illness, 'through the patient's eyes' (McWhinney 1989). Mead and colleagues introduce a greater complexity, suggesting implications both for the clinician's perspective – in terms of extending the biological to include the psychological and social in order to understand the patient's experience of illness - and for the clinician/patient relationship: a sharing of power and responsibility based on care, sensitivity and empathy, and attention paid to the human side of the doctor-patient relationship (Mead & Bower 2000). Thus, a recent review of interventions to promote patient-centredness identified as key features of care both a focus on the patient as a person, and the incorporation of power sharing between patient and clinician (Lewin et al. 2001).

An analysis of new roles for patients in the NHS by Angela Coulter adds two further dimensions (Coulter 2002). She describes 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 self-manager of his or her illness, and further as evaluator of his or her experiences of NHS services. It is this wider model of patient-centred care that seems to most closely fit understandings set out in key policy documentation: the NHS Plan (Department of Health 2000), NHS Improvement Plan (Department of Health 2004c), Children's NSF (Department of Health 2004a), Expert Patient (Department of Health 2001b) and Diabetes NSF (Department of Health 2001a) as table 1.1 below illustrates:

	Patient as decision-maker	Patient as self-manager	Patient as active citizen and evaluator
Diabetes NSF	"Diabetes services will be... developed in partnership: ensuring goals and the respective responsibilities of the individual and the diabetes team are agreed."	"Diabetes services will be person-centred: empowering the individual to ... manage their own diabetes through education and support."	
NHS Plan	"Patients must have more say in their own treatment."		"Patients must have more ... influence over the way the NHS works."
Children's NSF	"Children young people and their families are supported in self care of their illness in partnership with professionals."	"Children, young people and families are supported in self care of their illness."	"Children, young people and families receive high quality services which ... take account of their views."
NHS Improvement Plan	"Patients will work increasingly in partnership with professionals with the support of decisions aids and information to help them make the right choices .... Increasingly patients will be involved in decisions about their treatment and care."	"[The NHS] needs to enable people to take greater control of their own treatment."	"Person-centred and personalised... is [about] involving people themselves, and their families, in the design and delivery of those services."

Expert Patient	"The era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it services – one in which health professionals and patients are genuine partners seeking together the best solutions to each patient's problem, one in which patients are empowered with information and contribute ideas to help in their treatment and care."	"The challenge for the NHS, working in partnership with patient organisations and other government departments and agencies, is to bring about a fundamental shift in the way in which chronic diseases are managed – a shift which will encourage and enable patients to take an active role in their own care."	

Table 1.1 Understandings of patient-centred care in health policy documentation

The work of Patricia Sloper and her team at York University has amply described the state of the evidence in this last sphere: the young patient as health services evaluator. Their review of children's involvement in service development in the UK (Cavet & Sloper 2004) describes how, though the value of children's participation in service planning is now widely accepted, as in many other areas of public decision-making, its impact on service provision remains questionable: measured outcomes to date tend to relate to the personal development and understanding of children and staff involved rather than impact on services. More recent work considers Patient Advice and Liaison Services (PALS) as a mechanism for young people to contribute to service development. Researchers found that the design and development of PALS was not inclusive of young people's needs, and called for improvements in children's access to and awareness of PALS, and training for PALS staff in working with young people and their concerns (Heaton et al. 2008).

By contrast, this thesis aims to contribute to the evidence base on the first two spheres set out in the table above: engagement with children's experiences of managing their illness and day-to-day decision-making about care. It is a small point, but relevant, that successful self-management does not necessarily include overcoming the specific practical difficulties experienced by some patients and their carers in co-ordinating a range of different health and social care services. The importance of the role of key-worker in supporting children and families in this regard is recognised within the Children's NSF (Department of Health 2004b).

1.5 Type 1 diabetes in children

This study is undertaken from a sociological point of view. Perspectives on individual experiences of long-term illness in the social sciences are outlined in the next chapter. In this section I set out a brief overview of clinical information on type 1 diabetes, including the nature of the illness, incidence, prevalence, and key issues in its management. I end with an explanation of why I chose to use type 1 diabetes as a case study in this work.

Between 1972 and 1991, reported rates of child long-term illness more than doubled: a result of a combination of factors, including, perhaps, higher expectations of health, greater diagnosis of some conditions, and the impact of medical advances on the survival rates of some conditions (Blair et al. 2003). However there is also evidence of real and significant increases in incidence of diabetes in children, in particular type 1, especially in the early years (Gardner et al. 1997) and South Asian populations (Feltbower et al. 2002). Preventative interventions are still in the early stages of development (Zipitis & Akobeng 2008). Type 2, associated with obesity, and previously rare among children, is also becoming more common (Blair et al. 2003).

The prevalence of diabetes in England is about 1.62 per thousand children aged 16 or under, though there are significant country variations within the UK, for example prevalence in the same population in Northern Ireland is at 2.08 per thousand (Diabetes UK et al. 2004). Most children are diagnosed between the ages of 6 and 15 years (Healthcare Commission et al. 2005). The illness is more common among people with Asian and, to a lesser extent, African-Caribbean ethnic backgrounds (Sproston & Mindell 2004), but information on the ethnicity of children with diabetes is poor (Healthcare Commission et al. 2005; Diabetes UK 2004).

Type 1 diabetes is caused by failure of the pancreas to produce enough insulin to convert glucose in the body into energy. Although inhaled insulin is being developed for use with children (Adis International Limited 2004), and use of insulin pumps and continuous glucose monitoring systems is becoming more common, most children manage the illness via a daily regimen of blood tests, insulin injections, and maintenance of a healthy low-sugar diet. Children have to work the regimen into their daily lives, and deal with having painful injections and blood tests. They, and their carers, have to find an approach to care which balances the benefits of tight control to avoid diabetic ketoacidosis (DKA) - high blood glucose levels which increase the risk of later complications, such as eye, kidney and nerve disease – against the difficulties of a greater number of daily tests and insulin injections and the potential for hypoglycaemia - very low blood glucose levels which can cause faintness, unconsciousness, even coma and may impair normal brain development in young children (Shield & Baum 1998; Mortensen & Hougaard 1997): a balance that is very difficult to achieve (Eiser 1990). NICE recommends a glycaeted haemoglobin (blood glucose) level of 7.5% (National Collaborating Centre for Women's and Children's Health 2004a). In 2002/3 this was achieved by only 15% of the ten thousand children and young people included in the National Paediatric Diabetes Audit (Diabetes UK et al. 2004).

Research by psychologists has indicated that maintaining good care is easier for those with support from family and friends (Amer 1999) and positive family relationships (Miller-Johnson et al. 1994); and harder for those experiencing stress (Amer 1999; Bradley & Gamsu 1995), including stress about diabetes care (Anderson et al. 2002), and those with poor coping strategies (Amer 1999; Grey et al. 1991). Stress per se has been shown to increase blood glucose levels in children (Grey & Thurber 1991).

Perhaps it is not surprising that adaptation to diabetes is more difficult in families that are already experiencing difficulties and feel unsupported. In England, children with diabetes from deprived backgrounds have a greater tendency than their better off peers to experience the high blood glucose levels which increase their risk of later complications, such as eye, kidney and nerve disease (Healthcare Commission et al. 2005). Children with diabetes in Britain as a whole tend to have much less success controlling their blood sugar levels than children in other European countries (Scott & Donnelly 2001; Rosilio et al. 1998; Mortensen & Hougaard 1997). Although the UK is the fourth richest country in the world, recent history has seen a dramatic rise in relative poverty and exceptionally high levels of childhood poverty, particularly in London (Hood 2001) with significant consequences for the health and welfare of young people (Roberts 1997). I describe this further in the next chapter.

As with other long-term illnesses, a key aim for clinicians is to facilitate patient self-efficacy in day-to-day management (Clark & Gong 2000). This includes carers alongside children (Department of Health 2001a). Insufficient adult supervision of a child's treatment regimen (Wysocki et al. 1996) and lack of communication between carers and children around responsibility for diabetes care (Anderson et al. 1990) can be associated with poor control.

Prolonged hospital admission on diagnosis has been shown to be of negligible benefit for children (Clar et al. 2003). Ideally out-patient care is provided by a multi-disciplinary team comprising a paediatrician with a special interest in diabetes, a paediatric diabetes specialist nurse, and paediatric dietician with special interest in diabetes, and access to services in psychology, psychiatry, podiatry and ophthalmology (Betts & Swift 2003; Department of Health 2001a).

Diabetes treatment currently accounts for about 5% of NHS resources (Department of Health & Medical Research Council 2002). Yet, practitioners and families must manage paediatric diabetes care in clinical environments often short of appropriately trained staff (Jefferson et al. 2003), child-friendly information resources (Waldron et al. 1997) and using interventions predominantly developed for use with adults: of the 136 recommendations for the diagnosis and management of paediatric type 1 diabetes in the Diabetes NSF only a minority were based on randomized-controlled trials that included children (Burt et al. 2004). It is unsurprising that recent audits have found deficiencies in the standards of care for children and their families (Healthcare Commission et al. 2005; Jefferson et al. 2003).

There is a need for greater use of "tried and proven" (Scott & Donnelly 2001) methods to help children and young people manage their diabetes day-to day. Education alone is not effective (Fonagy et al. 2002). Promising approaches include self-management programmes informed by principles from behavioural science (Barlow & Ellard 2004; Bradley & Gamsu 1995); an intervention to offer greater dietary flexibility by teaching patients how to balance insulin and carbohydrate intake (DAFNE Study Group 2002); and use of IT systems to increase patient access to support (Farmer et al. 2005). Technologies which seem promising in research with young people include inhaled insulin, continuous glucose monitoring systems, insulin pump therapy, and provision of support via text messaging (Franklin et al. 2006; Torrance et al. 2003; Tamborlane et al. 2001).

Young children and boys tend to do better at achieving optimal blood glucose levels compared with older children and girls (Amer 1999). Findings from qualitative work directly eliciting the views of children and young people in the next chapter shed light on this.

1.6 Why type 1 diabetes as a case study?

Prior to this study, I had the opportunity to conduct some of the fieldwork on a project undertaken by colleagues at the Institute of Education, University of London (Sutcliffe et al. 2004). This involved one-off interviews, with children aged 12 years and younger with type 1 diabetes, and their parents, to explore, in particular, children's levels of responsibility, skill and knowledge in looking after their long-term illness alongside parents and clinicians. Findings focused especially on how traditional 'age-stage' theories of children's development underestimate children's competencies (Alderson et al. 2006a). This experience highlighted the extent to which characteristics of the type 1 diabetes care regimen make it a useful case study for exploring levers and barriers to patient-centred care with children. Care for insulin-dependent type 1 diabetes involves a relentless, daily regimen of blood tests, injections and judgement calls on diet and exercise, which, because of its intensity, intrudes much into children's day-to-day living. Thus, much more than with illnesses which require less frequent or complex interventions, children have extensive experiences of where there is harmony and where there is conflict between their own needs and the treatment regimen. Further, it is useful to study an illness where much of the intervention is carried out in domestic settings, since research with children has shown how children's relationships with adults are often more negotiated and their competencies more readily acknowledged at home compared with other environments (Mayall 2002; Mayall 1996; Mayall 1994a), and therefore there will be more opportunities to explore children's input into and impact on care.

Chapter 2: Children, minority ethnicity, health and long-term illness

Using type 1 diabetes as a case study, this work aims to contribute to understanding of how to improve services, in particular health services, for children in multi-cultural settings. This chapter describes the background literature relating to this. First I outline trends in poverty and health among children, and minority ethnic populations in the UK. I then move onto a discussion of the context in East London, where I carried out the fieldwork for the study. Finally, I describe what we already know about adults' and children's experiences of long-term illness.

2.1 Children in the UK: trends in poverty and health

Poverty is a strong determinant of health (Wilkinson & Marmot 2003). And, as I described in the opening chapter, we know not only that there is a significant (and widening) gap between the life expectancy of the most and least disadvantaged people in the UK (Department of Health 2005a), but also that there is a gradient linking socio-economic status with health across society (Graham 2006). Poverty is a problem which disproportionately affects children in the UK (Joseph Rowntree Foundation 2007). In the last 20 years of the twentieth century, changes to the tax and benefit system, unemployment and a rise in lone-parent families (Blair et al. 2003) brought a threefold rise in the proportion of children living in households with incomes of less than half the national average (after controls for families of different sizes), from 10% to 35% by the end of the 1990s (Bradshaw 2002). Since 1999/2000, this trend has been reversed (Bradshaw 2005). However, data from 2003 suggest that in the UK, the world's fourth largest economy, child poverty ranked 21st equal out of 27 European countries, alongside Poland and Greece (Bradshaw 2006). A 2007 UNICEF report found the material well-being of children in the UK to rank 18th out of 21 nations in the industrialised world (Unicef 2007). While the Government's welcome commitment in 1999 to eradicate child poverty over the next 20 years has brought about a valuable cross-party consensus on the importance of tackling this issue (Joseph Rowntree Foundation 2006), a particular focus within this on improving parental employment (Law 2003), which overlooked the fact that half of children in poverty are in families where someone is already working, alongside failure of provision for children in non-working households to keep pace with rising wages and incomes (Palmer et al. 2006), has meant that actual impact to date has fallen short of, albeit ambitious, targets.

It is then not surprising that a report in 2005 found that while children's health is improving in some areas – infant mortality, accidental death, serious infections and reported good health - overall the health of children in the UK continues to be a cause for concern, particularly since in some respects, gaps between health outcomes for the most and least advantaged are widening (Hargreaves 2007; Smith et al. 2007; Department of Health 2005a; Health Protection Agency Centre for Infections 2005). In 2005, the percentage of low birth-weight (a strong indicator of later health) and stillbirths, failure to take-up MMR vaccine, and rates of HIV/AIDS, asthma, diabetes, obesity, measles and mumps, sexually-transmitted diseases, and conduct, hyper-activity and emotional disorders were all on the rise. Comparison with other countries shows that while the UK infant mortality rate may be falling, it is still higher than most other European countries (Bradshaw 2002). A 2007 report commissioned by UNICEF on children's well-being ranked the health and safety of children in the UK 12th in an overview of 21 industrialised nations (Unicef 2007).

About a quarter of children in England have a long-standing illness, and this is higher in lower socio-economic groups (though the opposite is true in relation to type 1 diabetes) (Beresford 2002); further, prevalence of long-term illness is rising faster amongst children than amongst other age groups in the UK (Beresford 2002). Most common are respiratory conditions, followed by skin conditions and then musculoskeletal illnesses. The influence of socio-economic position on health also works in the other direction for those with long-term illness, so that adults with long-term illness or disability not only have a lower social status, but also lower incomes, and fewer assets than others (Townsend 1979). Much of this relates to the lower employment rates amongst adults with long-term illness, so is not directly relevant to the children in this study; though, it is indirectly so, since we know that children with long-term illness are very likely to have a parent also with long-term illness (Townsend 1979) and that in turn will affect wealth and social status for the whole household. Further, the impact of caring for a child with long-term illness may also impact on carers' ability to do paid work, which again in turn affects the wealth and status of the whole family (Sloper & Beresford 2006).

2.2 Minority ethnicity in the UK: poverty and health

In the 2001 UK census, 92% of people identified themselves as having a White ethnic background. Of the remaining 8%, most others described themselves as Indian (1.8%), Pakistani (1.3%), Mixed ethnicity (1.2%), Black Caribbean (1%), Black African (0.8%), Bangladeshi (0.5%) or Chinese (0.4%). These populations are not evenly distributed about the country but tend to be concentrated in large, urban areas (National Statistics website 2008a). It is these which comprise the 'multi-cultural' settings to which I refer in the stated aim of this study.

Ethnicity is as a fluid concept drawing on understandings of shared origins, cultures, languages or religious traditions, and varying according to the context in which the definition is made (Senior & Bhopal 1994). Children born in the UK to parents from outside the UK may have a different ideas about their ethnicity from their parents: for example seeing themselves as members of a larger, less specific group than the parents (Indian, instead of Sikh Punjabi) and may include a reference to their country of birth (British Indian) (Senior & Bhopal 1994). Ethnicity is distinct from race, where categorisation is by physical characteristics. Race may be a useful concept to some extent in assessing probability of risk for certain diseases in relation to origin (Senior & Bhopal 1994), but categories are largely arbitrary in terms of genetics: no race possesses a discrete package of genetic characteristics and there is more genetic variation within races than between them (Senior & Bhopal 1994).

The use of ethnicity in population-based data is not entirely unproblematic. People may define themselves differently at different times; broad categories often mask important differences, for instance around country of origin, socio-economic background, religion, language, or diet; and researchers may tend to use data about the majority ethnic group as a yardstick for all other data, missing key issues in the minority group (ethnocentricity) (Spencer 1996; Senior & Bhopal 1994). These are challenges particularly, though not entirely, for epidemiology. Their implications in qualitative work are different and I discuss this further in Section 5.1 of the fieldwork findings (Chapter 5). At this point it is sufficient to point out that simple demographic data can mask a huge diversity of human beliefs, experiences and culture.

While there is considerable prosperity amongst some ethnic groups (Berthoud 2002), poverty and unemployment are problems which disproportionately affect people with minority ethnic backgrounds in the UK, and in particular those with Bangladeshi, Pakistani or Black African backgrounds (Joseph Rowntree Foundation 2007; McLuckie-Townsend 2003; Karlsen & Nazroo 2002; Spencer 1996). A recent study has explored how poverty affects people from different ethnic backgrounds differently (Joseph Rowntree Foundation 2007). This found the problem to be most extreme and most sustained amongst Bangladeshi people in the UK, nearly two-thirds of whom live in poverty. However people with Caribbean backgrounds were found to experience the greatest levels of anxiety about finances; and the lack of informal social support often associated with experiences of poverty does not seem to affect people with Bangladeshi and Pakistani backgrounds as much as one might imagine, given the extent of poverty amongst these populations; rather this has been a problem found to particularly affect Black Caribbean and Black African people, in particular women (Joseph Rowntree Foundation 2007).

Unsurprisingly, given what we know about the impact of socio-economic factors, overall the health outcomes for those from minority ethnic backgrounds are poor in relation to majority groups (Joseph Rowntree Foundation 2007; Berthoud et al. 1997), particularly for people with Bangladeshi or Pakistani backgrounds (Sproston & Mindell 2004). This is despite the fact that some important health behaviours, such as fruit and vegetable consumption and not drinking alcohol, are more common amongst most minority ethnic populations than in the general population (Sproston & Mindell 2004). The role of both genetics and/or 'culture' in accounting for ethnic inequalities in health has been greatly exaggerated (Greenhalgh 2005; Spencer 1996) at the expense of recognising causes rooted in poverty and discrimination (Karlsen & Nazroo 2002; Overstreet et al. 1997; Spencer 1996). People from ethnic minorities suffer racism not only on an individual, but also an institutional level, when services are organised around a 'white norm' and/or essentialist ideas of the needs of people with 'other' ethnic backgrounds (Roberts & McNeish 2005; Atkin & Rollings 1996; Watters 1996). Further, protective factors which first generation migrants may bring with them - healthy diets and community attachment for those from countries that have established communities in the UK – may be eroded over time by psychosocial risk factors associated with the stress and losses of migration and wider socio-economic exclusion; alongside the uptake of alternative behaviours such as smoking and physical inactivity, with their attendant physical health risks (Australian Government & National Health and Medical Research Council 2005; Sproston & Mindell 2004).

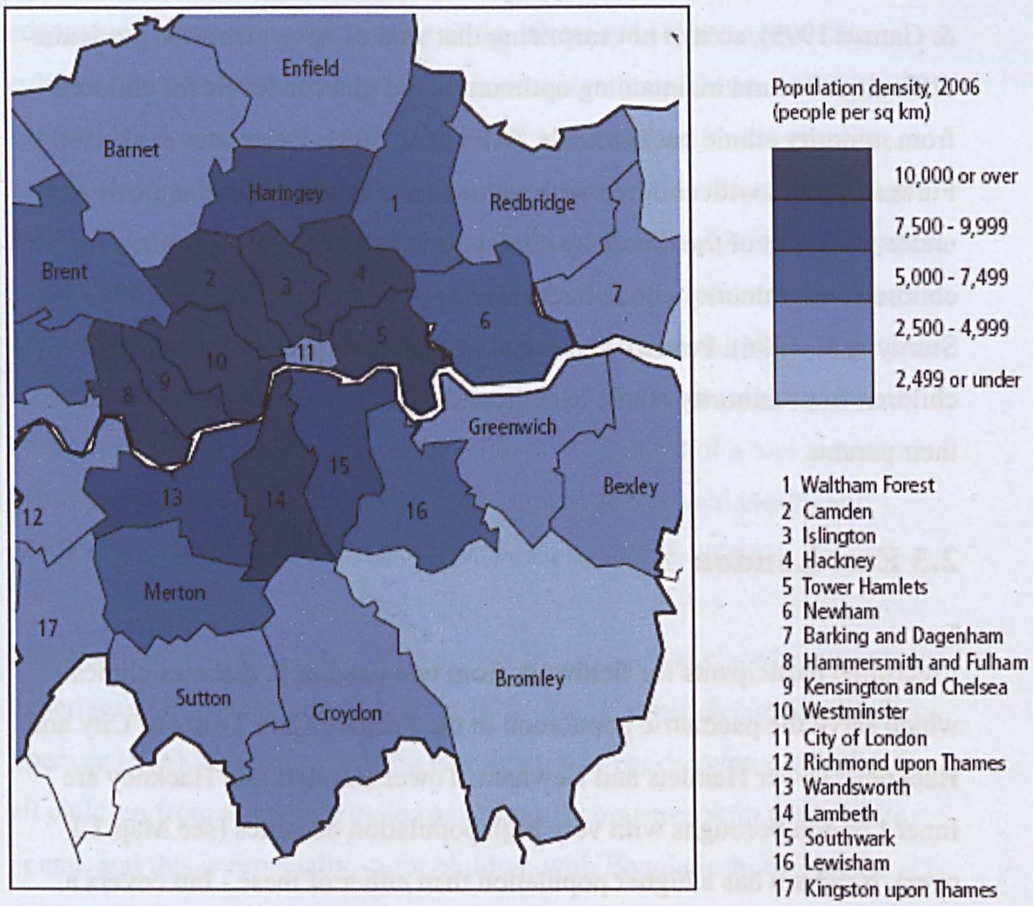
It is ironic that while poverty remains a defining experience for many people from minority ethnic backgrounds, it is ethnic, religious, and linguistic differences that are the central focus for best health care practice in multi-cultural settings (Australian Government & National Health and Medical Research Council 2005; Helman 2005; Helman 2001). That is not to deny the fundamental importance of individual and in particular, organisational competence in these areas. Valuing diversity, being capable of cultural self-assessment, and conscious of the dynamics that occur when cultures interact is important; and cultural knowledge must be institutionalised and delivery adapted to reflect an understanding of the diversity between and within cultures (Australian Government & National Health and Medical Research Council 2005; Department of Health 2005b). Key areas for intervention have been identified as proper monitoring of ethnic diversity and language for planning and resource allocation; research to build a culturally competent evidence-base in health promotion and service delivery; and more resources and better training for professional development around cultural competency, including a focus on ensuring information on people from minority ethnic backgrounds is used as a context for interaction, instead of a tool to assume behaviours and beliefs (Australian Government & National Health and Medical Research Council 2005; Department of Health 2005b).

Since people from minority ethnic groups in the UK and elsewhere routinely experience high social and economic exclusion (Karlsen & Nazroo 2002; Spencer 1996), it is not surprising that the risk of child poverty is higher for all children from minority ethnic backgrounds compared with their White peers; and this is especially so for children with Bangladeshi or Black African backgrounds (Joseph Rowntree Foundation 2007; Bradshaw 2002). A 2003 overview of the ethnicities of children in households in the bottom fifth of the income distribution in the UK found only 18% of children to have a White ethnic background, compared with 61% of Bangladeshi and Pakistani children, 43% of Black non-Caribbean children, 34% of children with Caribbean backgrounds and 26% of Indian children (Marsh & Perry 2003).

Across all generations diabetes is more common amongst people who have Pakistani, Indian, Bangladeshi and, to a lesser extent, African-Caribbean ethnic backgrounds (Sproston & Mindell 2004). Information on the ethnicity of children with diabetes is poor (Diabetes UK et al 2004; Healthcare Commission et al. 2005); however there is evidence of significant increases in incidence of type 1 diabetes in children with South Asian backgrounds (Feltbower et al. 2002), relating to the impact of environmental factors around living in the UK (Raymond et al. 2001). We know that managing diabetes is more difficult for those experiencing stress (Amer 1999; Bradley & Gamsu 1995), so it is not surprising that studies have identified particular difficulties around maintaining optimum blood glucose levels for children from minority ethnic backgrounds (Alvi et al. 2001; Delamater et al. 1991). Further, studies with children with asthma have found under-diagnosis and under-treatment of the illness by clinicians to be a particular problem for children with minority ethnic backgrounds (Duran-Tauleria et al. 1996; Sturdy et al. 1996). Poverty and social exclusion impact on the health of children from minority ethnic backgrounds, just as they do on the health of their parents.

2.3 East London

I recruited participants for fieldwork from two paediatric diabetes clinics which serve the paediatric population in the Primary Care Trusts of City and Hackney, Tower Hamlets and Newham. Tower Hamlets and Hackney are Inner London boroughs with very high population densities (see Map 2.1 over). Newham has a higher population than either of these - but covers a larger area, has a much lower population density, and is in Outer London (Office for National Statistics, 2008b). The City of London has a very small residential population: over 43 times the number of residents come into the borough to work during the week. Within this, the proportion of people aged under 16 is extremely low (Department of Planning and Transportation 2005). For this reason, my description of the setting in the next few paragraphs will focus on the other three boroughs.



Source: National Statistics website: www.statistics.gov.uk. Crown copyright material is reproduced with the permission of the Controller Office of Public Sector Information (OPSI).

Figure 2.1 Section of map of population density of London by borough, 2006

Given that this study aims to contribute to understanding of health service delivery to children in multi-cultural settings, it is appropriate that fieldwork should take place in East London. In the 2001 census, most people in Hackney identified themselves as having a White ethnic background (60%), but there is also a large African/Caribbean population (25%) in that borough (Office for National Statistics, 2008b). In Tower Hamlets, most people described themselves as coming either from a White (42%) or Bangladeshi background (33%) (Russell et al. 2005). Eighty per cent of all Bangladeshis in London live in Tower Hamlets; most Bangladeshi adults there are

Bangladeshi-born, but most Bangladeshi children are UK-born (Office for National Statistics, 2008b). In Newham, again, a White ethnic background is most common (40%), though in this borough there is no single other main ethnicity: people described themselves as Indian (12%), Pakistani (8%), Bangladeshi (9%), African (13%) and Caribbean (7%) (London Borough of Newham 2006). In a 2001 survey of 3000 children in 28 East London schools, 60% of children identified themselves as having a minority ethnic background. Twenty per cent reported being born outside the UK (Stansfeld, 2003).

It is also appropriate that work concerned with issues of inequality should be carried out in East London. From the seventeenth century, when Huguenots fleeing persecution in France - and excluded from the City of London by the powerful guild system - settled on the eastern outskirts in Spitalfields, to the Irish and Jewish immigration of the eighteenth and nineteenth centuries, and immigration from Pakistan and Bangladesh, and more recently, Somalia, in the twentieth century, East London has a long history of providing home to those trying to escape poverty or persecution elsewhere. But the demise of the weaving industry at the end of the eighteenth century (Engels 1993) itself brought poverty to this previously affluent area; and though better sanitation and housing, and immunisation programmes have dramatically improved health across rich nations in the last 150 years, some might argue that class differences now are not so dissimilar from when Charles Booth's famous surveys charted the extreme deprivation of the East End in the 1880's (London School Economics and Political Science website 2008). Despite their proximity to the wealthy business districts in the Square Mile and Canary Wharf, 57 of the 58 wards in Tower Hamlets, Newham and Hackney are amongst the 25% most deprived in the country, and life expectancy for people in over half of these is significantly lower than in the rest of England. All three boroughs experience high levels of violent crime, and a high proportion of local authority housing in Hackney and Tower Hamlets is of poor quality (Community Health Profiles website 2008).

Figures from 2002 suggest that Tower Hamlets has the highest concentration of child poverty of any local authority in England (Bradshaw 2002): 59% of its children live in poverty (Community Health Profiles website 2008). In Newham infant mortality rates (historically strongly linked to social deprivation) are significantly high in comparison not only to other boroughs across England, but even in comparison with other London boroughs (McNeish et al. 2007). Both Newham and Tower Hamlets have high levels of people recorded as having either type 1 or type 2 diabetes compared with other areas (Community Health Profiles website 2008) and Tower Hamlets has the highest rate in London of type 1 and type 2 diabetes amongst those under 30 years old (McNeish et al. 2007). Air quality in Hackney and Tower Hamlets is poor, even for London, where levels are high (Community Health Profiles website 2008) and these two boroughs, along with Islington, have the highest admissions to hospital rates for respiratory difficulties in people under 20 years old in London (McNeish et al. 2007).

Of 3000 children aged 11 – 14 years who took part in a survey in 28 schools in East London in 2001: nearly 40% had neither parent employed, nearly 50% were eligible for school meals, nearly 30% lived in over-crowded households, and nearly one third said they did not feel safe in their local community (Stansfeld 2003). Levels of self-reported general health were lower, and psychological stress and obesity higher, than elsewhere, though children reported similar or lower levels of smoking and alcohol consumption compared with the rest of the country.

2.4 Experiences of long-term illness in adults

In the second part of this chapter I turn from consideration of population data on illness amongst children and minority ethnic populations, to explore understandings of experiences of long-term illness, first, amongst adults, since it is these that have influenced subsequent accounts of children's experiences (see Section 2.5). The following is based on a framework by Michael Bury (Bury 1991), though the perspectives of Talcott Parsons, Symbolic Interactionists such as Erving Goffman and Anselm Strauss, and other authors are also significant.

2.4.1 Initial (and ongoing) disruption

Bury describes disruption across three spheres: day-to-day activities, personal and social identity and thirdly, in relation to resources, both social and material.

a) Consequences of the illness for day to day life

This refers to the management, perhaps tentatively at first, of the effects of symptoms or treatment (Bury 1991). Ironically, the physical realities of living with a sick body have been relatively absent from writing about people's experiences of long-term illness (Kelly 1996; Kelly & Field 1996). Mike Kelly has pointed out that coping with the physical body is a pressing, immediate task for those with long-term illness, more so than dealing with relationships and social disruptions (Kelly 1996; Kelly & Field 1996).

b) Significance of the illness for personal identity

The frame of reference here is firmly based in Parson's account of illness as socially undesirable, whereby restitution is only possible via a process of striving for, and ultimately achieving wellness (Parsons 1951) - and therefore, largely unavailable to those with long-term illness, who are unlikely to be able to fulfil the 'obligation to get well' (Kelly & Field 1996). From time to time, those with long-term illness may experience periods when, with co-operation with expert help, an improved state of wellness comes about - for example after an operation or on first being diagnosed (Bury 1982). However, on the whole, long-term illness, or disability, regardless of the nature of attendant characteristics, is seen as socially undesirable and as such impacting on personal and social identity.

Of course this cannot always be so. Erving Goffman's account of the management of socially undesirable characteristics - a useful framework for thinking about managing social identity in long-term illness in itself - makes clear that no specific attribute is intrinsically socially undesirable (or desirable), but derives its quality from context (Goffman 1963). A young person may try to hide her diabetes from school friends but in the context of a support group it becomes her passport to membership.

Drawing on Goffman's account of the management of stigmatising traits (Goffman 1963), Bury suggests that significance of the illness for identity will relate to changes in the extent to which symptoms intrude into social situations (Bury 1991). Along similar lines, Kelly flags up the importance of the bodies of the chronically ill beyond the realm of the physical, in terms of impact on self-perception and social identity (Kelly 1996; Kelly & Field 1996). Kathy Charmaz has described how the impact of the ill body on public identity in turn affects self-perception leading to a feeling of 'loss of self' which can result in social isolation (Charmaz 1983). Goffman has described how individuals can be 'betrayed' by their physical body – either by the on-going obtrusiveness of symptoms or when the individual is 'caught out' by the onset of symptoms such as hypoglycaemia (Goffman 1963). Bury adds that the significance of the illness for identity will also relate to changing social stereotypes that are attached at different times in history to different illnesses, at different stages in the life course. He identifies these processes as characterised by uncertainty as the individual explores the extent to which their own changing understandings and needs around the illness are met (or not) by others. Processes of diagnosis may also be characterised by an extended period of uncertainty, with either relief at reaching a fixed diagnosis at the end, or fear accompanying particularly stigmatising diagnoses such as epilepsy or cancer (Bury 1991).

c) Disruption to resources

In an earlier section of this chapter, I described the negative impact which long-term illness or disability has on economic resources (Townsend 1979). The discussion here captures the same effect via evidence from qualitative studies of the experiences of individuals. In a paper predating his review of the sociology of long-term illness Bury flags up disruption to resources, both social and economic, available to deal with the new situation brought about by the illness (Bury 1982). He, and other commentators, describe how invaluable social networks may be disrupted not only by growing physical limitations associated with illness, but by the sufferer's wish to isolate herself to avoid social embarrassment (Strauss et al. 1984; Charmaz 1983; Goffman 1963). In David Locker's study of 24 adults with rheumatoid arthritis almost all participants had given up their jobs because of the illness and this had a huge impact both socially and financially (Locker 1985; Charmaz 1983).

To return to the overall theme of disruption, Bury specifies the importance of recognising the dynamic nature of the experience of long-term illness and how its meaning in someone's life changes as different stages in the illness interact with the different stages of an individual's life. This draws on Strauss' (Strauss et al. 1984) concept of the illness 'trajectory' which he used to designate all the work, by patient, family and clinicians, that goes on in the temporal course of the illness. His exposition of this highlights how, while initial experiences of symptoms or diagnosis, cause the first experience of disruption, every subsequent change in the anticipated illness trajectory, both in terms of the illness itself or the context in which it is cared for, will cause yet more disruption. Bury suggests that an overarching theme within symbolic interactionist studies of long-term illness is the idea of long-term illness 'as a major kind of disruptive experience' (Bury 1982) - and that as such it might be considered one of Gidden's 'critical situations' where a great deal can be learned about a situation precisely because of the extreme degree of disturbance to it (Giddens 1979).

2.4.2 Explanation and 'legitimation'

Bury uses the word 'legitimation' to refer to the processes of finding explanation which set in after the initial onset of illness (Bury 1991). These will involve trying to repair the disruption, especially to personal identity and social status, caused by the onset of illness, as already described. Goffman's analysis of management of damage to social status by 'passing' or hiding stigmatizing characteristics where possible - or where it is not, 'covering', or reducing their impact on the social setting is useful, but incomplete in that it gives no description of the internal journey whereby 'the stigmatized individual can come to feel that he should be above passing [or hiding his stigma] that if he accepts himself and respects himself, he will feel no need to conceal his failing' (Goffman 1963, p125).

Building on the work of Gareth Williams, Bury suggests that 'the biological arbitrariness and caprice' (Williams 1984, p 182) of medical explanations will be insufficient to support legitimation. Williams found that participants in his study of experiences of rheumatoid arthritis incorporated alongside, or supplanted, medical explanations with more meaningful explanations which drew on biographical details, and aimed to reconstruct the disruption to identity caused by the illness. There was one interesting exception to this: a woman whose strong religious belief exempted her from the psychological task of accounting for the relationship between her sense of self, her illness and the rest of the world. This connects with the work of General Practitioner (GP) and anthropologist Cecil Helman (Helman 2005; Helman 2001), who has flagged up the huge impact that an individual's culture will have on the nature of processes of adaption. He suggests that narratives from traditional healers outside the world of clinical medicine - either spiritual or from alternative health care systems - may help.

Charmaz makes a useful comment on what might be assumed to be a common form of legitimation - the recasting of suffering as 'a path to knowledge and self-discovery' (Charmaz 1983, p191). She observes how none of the people in her work used this way of thinking about their difficulties, and suggests that such an approach is perhaps only ever pertinent in retrospect, as a rationalization of earlier suffering once the individual experiences a more hopeful present. This renders it of little use to those still struggling with processes of legitimation.

Bury notes how the battle for legitimation may complicate cooperation with clinicians. While the clinician is concerned mainly with medical goals, the individual with long-term illness may be more concerned with personal ones. This clarifies the processes underlying Goffman's (Goffman 1963) observation that the individual may take a strong dislike to using equipment associated with their illness – which in turn leads us onto the third aspect of Bury's analysis of the experiences of long-term illness.

2.4.3 The impact of treatment regimes

Modern advances in medical science may improve the quality of life of those with on-going illness, though this is not necessarily always the case. Bury uses Robinson's (Robinson 1988) image of the 'medical merry-go-round' to describe how individuals may end up in exhausting pursuit of new technologies or interventions where hopes are continually raised and then dashed again as advances prove less useful or more limited than had been hoped (Bury 1991).

Bury also makes the point that the term 'compliance' in relation to a person's decisions about treatment is inappropriate. The process of decision-making for those with long-term illness – and indeed their doctors/nurses and anybody else – is not so simple as merely whether or not to 'follow doctor's orders'. The individual with long-term illness is likely to make decisions about their illness in terms of trade-offs between their medical knowledge, their own agenda for themselves and larger cultural or social pressures (Bury 1991). Bury cites Robinson's (Robinson 1988, p 84-5) description of how 'a pooling of their respective medical and complementary expertise may facilitate the achievement of some of their goals'. Other commentators have suggested that compliance be replaced with the concept 'concordance' which more aptly captures the complexity of working together on such processes (Sanz 2003).

An important aspect of patients' experiences of treatment is their experiences of clinicians and the nature of interaction in clinical settings. As has already been pointed out, the priorities of clinicians and patients are often different. Clinicians are concerned with disease-management (Bury 1982) and (especially consultants) maintaining professional standing (Friedson 1970), whereas their patients are concerned with the wide range of issues already outlined above. Some studies have suggested that clinicians' feelings about patients may be linked to whether those patients make it easy or difficult for clinicians to carry out their caring role. Those with long-term illnesses - along with those with rule-breaking behaviour and of different racial groupings to medical staff, or who speak different languages - may be amongst those more readily perceived as troublesome (Kelly & May 1982). Robert Dingwall's study of perceptions of children in acute settings found children to be immune from categorisation as 'good' or 'bad' patients (Dingwall & Murray 1983). Yet undoubtedly this did not extend to their carers and it seems likely children would be affected by the views of the clinician on them. I discuss children's interactions with clinicians further in Section 2.5.6.

2.4.4 Coping, strategy and style

Bury concludes his overview of experiences of long-term illness by suggesting that there are three key aspects to the process of adapting to long-term illness (Bury 1991).

'Coping' he designates as the psychological processes of learning to put up with the effects of the illness. This involves maintaining feelings of self worth, both in relation to oneself and to others, and is often seen as an important protection against the stresses of illness. Bury suggests examples of this may be either 'bracketing off' the illness from, or strongly incorporating the illness within one's internal identity (Bury 1991).

'Strategy' refers to concrete actions undertaken, for example, withdrawing from some aspects of social life in order to avoid the illness impacting in this arena (Charmaz 1983; Goffman 1963).

'Style' concerns the way in which the individual presents the illness or treatment regimen to others (Bury 1991). Bury cites two contrasting examples of these from Alan Radley's (Radley 1989) study of the management of heart disease. He recounts how the 'accommodation' style requires 'elaborated' communication with others and as such provides opportunities for flexibility around how symptoms are presented. Whereas the 'active-denial' style only requires restricted communication and involves opposing the illness via 'increased engagement in everyday activities'. These two styles of presentation seem to mirror two commonly described approaches to psychological coping – 'bracketing off' the illness from one's identity, or 'incorporating it more fully'(Bury 1991). Authors of a study of adults with diabetes strongly favour the second approach (Zoffmann & Kirkevold 2005), but Bury (Bury 1991) and Radley (Radley 1989) warn how divergent approaches to style may originate from strongly differing ideas about health and the body embedded in structural factors. Style will be strongly affected by the 'cultural repertoire' available to an individual. As such a prescriptive approach to adaption to long-term illness is unlikely to be helpful.

2.5 Children's experiences of their health and illness

In this section I describe some of the work that has been carried out to explore children's experiences of their health and illness, particularly, though not exclusively, experiences of diabetes and asthma. I focus on studies mainly within sociology and anthropology, since those are the disciplines in which the view of childhood I set out in the introduction is most commonly found. This is not intended to be an exhaustive summary, but an overview within which I highlight the main themes that are important in setting the context for this work.

2.5.1 Children's health competence and understanding

Studies of children's lives have brought to public view the work children do in relation to maintaining their own health (Mayall 2002; Christensen 1998; Mayall 1998; Mayall 1996; Mayall 1994a). This has shown that children – not just children with long-term illnesses - consider themselves key health carers with relevant expertise and experience (Christensen 1998; Mayall 1994a). For example, in Christensen's ethnographic study of 6 – 11 year-olds in Copenhagen, children's accounts of day-to-day medical interventions emphasised the importance of their co-operation in these therapies (Christensen 1998).

Christensen's anthropological work has explored how young children experience their bodies, their health and illness. She describes - and this is reiterated in empirical work by others, including those working with children with type 1 diabetes - how, in the early years, children's understandings of illness are rooted strongly in the subjective, physical sensations of their body (Penza-Clyve 2004; Sutcliffe 2003; Christensen 2000; Christensen 1999). At the same time, children also begin to learn an objective, bio-medical view of the body, their learning encouraged, for example, through body-part naming games and rhymes (Christensen 2000; Christensen 1999; Williams & Bendelow 1998). Christensen's work has also highlighted how, like adults, children experience illness as a social event (Christensen 2000), identifiable via disruption to normal, daily activities: "I was lying in bed for three days reading Donald Duck, then I got well and went back to school" (p192) (Christensen 1998).

For a long time, adults' views of children's understandings of illness have been heavily influenced by ideas from developmental psychology about children's conceptions progressing through a hierarchy of stages at specific ages; whereas more recently commentators have emphasised the impact of children's social experiences on understanding (Lorrie Yoos 1994; Eiser 1989). Sociological studies with children, including very young children, have found those with extensive experience of illness knowledgeable about their illness and treatment (Datta et al. 2004; Bluebond-Langner 1978). For example, in relation to asthma, both teenagers (Gabe et al. 2002) and children as young as seven (Kohlman Carrieri et al. 1991) show independence and resourcefulness in managing their illness, using strategies little different from those used by adults. Likewise, a study by Priscilla Alderson with 120 children with severe illnesses and their parents and 70 health care professionals (Alderson 1993) found children's competence not specifically related to age, but to individual experiences, particularly of high adult expectations of competence (or not). It also varied by children's inner qualities, such as confidence, memories and abilities. Some carers felt that when medical information was carefully explained their 3 or 4 year-old child could understand it as well as any adult. Exceptional 5 or 6 year-old children were found to be able to make complex decisions.

Though children see themselves as competent health carers, some work has indicated that children do not necessarily see all health care work as their responsibility. For example, a study of attitudes to eating fruit and vegetables found that they did not regard choosing 'healthy' food options as their responsibility (Thomas et al. 2003). Even in relation to decisions into which young people are clear that they do want to have input, they have stressed the importance of joint, rather than sole responsibility. In Alderson's study with children with severe illness aged 8 – 15 years (Alderson 1993), few said they wanted their parent to be the 'main decider' in decisions about treatment. However, equally, most were also cautious about the amount of responsibility for decision-making they could cope with alone, and wanted to take decisions jointly alongside their parents.

2.5.2 Adults as arbiters of children's health and illness in different settings

Christensen has identified the role of adults as arbiters of children's experiences of illness. Her observations of children in Danish schools revealed how adults did not deem children's subjective experiences sufficient to identify 'real' illness, but rather as a prompt for their own investigations, based on knowledge and equipment from bio-medical models : "I felt ill, then dad took my temperature and he said, yes you are ill' (Christensen 1998, p192). She contrasts this with the non-judgemental 'looking' in which children engage in response to peers' calls for attention to their hurts and minor injuries, and suggests that adult anxiety about the unboundaried nature of children's subjective experiences may contribute to desire to quantify and objectify children's experiences (Christensen 2000). She also observes how, while in day-to-day life adults encourage children to be 'feisty' and active, in interactions around illness, they are, on the whole, rendered incompetent and passive (Christensen 2000) – which echoes Bloor's comment about adult patients being expected to judge when to consult a health practitioner, but then become completely passive in subsequent interaction with them (Bloor

& Horobin 1975). She notes how this behaviour hinges around very generalised notions of children's vulnerability which fail to achieve more nuanced understandings of the different ways in which different children may or may not be vulnerable at different times and in different settings (Christensen 2000).

Mayall's studies of children's lives have also found adults may overlook children's expertise and experience around their health. Her observational work in schools in England found that parents and teachers excluded children from dialogues about their health (Mayall 1994a), and that children's expertise was particularly ignored in school settings – as opposed to home - where the intellectual and cognitive is valued above the physical (Mayall 1996). She found arrangements for children's health in schools to be maintained mainly through tacit understandings and ad hoc negotiations whereby teachers monitored and diagnosed children, helpers provided hands on care and school secretaries carried out liaison with parents (Mayall 1994a); and that children did not see the teacher as a health care worker since concerns about illness were normally dismissed or referred on to helpers or the secretary (Mayall 1996). Mayall argues that in the home the personal relationship between parents and children, and parents' vested interests in passing some responsibilities to children, provide a framework for the child to demonstrate competence, including around health care (Mayall 1994a; Mayall 1994b).

Children's awareness of how stereotypes of adult competence and child incompetence are played out in interactions around everyday illness are indicated in their recognition of the social hierarchies that exist around access to medications. Christensen observes that children associate independent access with improved social status: "I am just as big as David now" says a boy who is given a bottle of nasal spray to use, referring to his brother who has asthma, and hence, independent access to his medications (Christensen 1998, p 198). She describes how, because adult notions of childhood do not readily encompass competent use of medicines, children with long-term illness who do need independent access to their medications are, instead, regarded as different from other children (Christensen 1998).

2.5.3 Children's experience of long-term illness as physical disruption

Helvi Kyngäs' qualitative work with Finnish teenagers with type 1 diabetes in the 1990's (Kyngäs & Barlow 1995) provides a useful framework around which to structure current knowledge about young people's experiences of long-term illness, in particular diabetes. The extent to which these prove similar or different to the experiences of younger children will become clear in the course of this study. In line with Bury's work which found adult experiences of long-term illness to be characterised by disruption across many different aspects of life, so Kyngäs found teenagers' experiences also to centre around disruption, at physical, psychological and social levels. And just as Kelly's work has highlighted the impact of caring for the sick body as a dominant experience for adults with long-term illness (Kelly 1996; Kelly & Field 1996) so Kyngäs found teenagers identified their experiences of the intervention as physically painful and damaging because of regular insulin injections. Discomfort from injections is also raised by children and young people in research which has included younger children alongside teenagers (Fox 1995; Ory & Kronenfeld 1980). Likewise, the authors of work with young people with asthma report that feeling pain and 'feeling ill' are central to their experience of illness (Penza-Clyve et al. 2004; Gabe, Bury & Ramsay 2002; Yoos & McMullen 1996).

Young people in Kyngäs'work (Kyngäs & Barlow 1995) and other studies (Standiford et al. 1997) identified future complications (for example, kidney or sight or circulatory problems) as another potential threat to physical well-being, alongside current threats from variable blood glucose levels: "I may not survive the next hypo. I will not be alive" (Kyngäs & Barlow 1995). The possibility of sudden death is also raised by young people with asthma (Gabe et al. 2002; Rich & Chalfen 1999; Clarke 1992).

2.5.4 Children's experience of long-term illness as social disruption

I have already described how Christensen's work has flagged up the extent to which young children (like adults) understand illness as a social event (Christensen 1999): for example, one seven year-old Danish girl describes what it means to be well again in terms of 'To do as I normally do' (Christensen 2000, p 46). This perception of illness in social terms is extensively borne out in empirical work with children and teenagers with long-term illnesses, including those with diabetes (Sartain et al. 2000). Researchers have found many young people's experiences to centre around the social consequences of the restrictions which their illness or its medical regimen imposes on their daily lives (Ellerton et al. 1996) - for example limitations arising out of dietary restrictions for those with diabetes (Sartain et al. 2000; Kyngäs 1999; Kyngäs & Barlow 1995; Kyngäs & Hentinen 1995; Ory & Kronenfeld 1980) or physical activity for those with asthma (Penza-Clyve et al. 2004; Gabe et al. 2002; Chadwick 1996; Yoos & McMullen 1996). One teenager formulated this in terms of "I think asthma controls me, I don't control it" (Rich et al. 2002). Several researchers have found that the manifestation of these restrictions in young people's day-to day lives give rise to feelings of difference from peers (Callery et al. 2003; Amer 1999; Rydstrom et al. 1999); may result in teasing (Chadwick 1996); and can account for the overriding priority amongst most young people of being 'normal' or the 'same' as peers (Buchbinder et al. 2005; Gabe et al. 2002; Rydstrom et al. 1999; Kyngäs & Barlow 1995) - even sometimes, if necessary, at the expense of maintaining good health (Prout et al. 1999; Kyngäs & Hentinen 1995).

Prout's study of 11 and 12 year-old children with asthma found the asthma inhaler to be a considerably more attractive intervention than life-style changes since this could be used with minimal alteration to 'ordinary life' and as such achieved a sort of charm-like status for users (Prout et al. 1999). This contrasts with findings from Jonathan Gabe's work with 11-16 year-old young people which found that though young people were not concerned about using the inhaler in public, they did have some reservation about regular use because of worries about 'dependence on unnatural substances'

(Gabe et al. 2002, p1631). While other studies have also found young people to be comfortable with using the inhaler in public (Chadwick 1996), findings from some others suggest that this is not always the case, perhaps particularly for younger children (Rich & Chalfen 1999; Clarke 1992). Equally, a small survey of children with diabetes found young people's feelings about wanting privacy for injecting to differ, where this was important for some and not for others (MacArthur 1996). Several studies with teenagers with diabetes have found young people's differing preferences for openness or reserve around their treatment regimen to divide along gender lines (Buchbinder et al. 2005; Williams 2002; Williams 1999); Clare Williams has identified young women as accepting of their illness so that this is assimilated into their identity, in contrast with young men who remain concerned to keep the illness as socially invisible as possible (Williams 2002; Williams 1999).

2.5.5 Children's experience of long-term illness as psychological disruption

Teenagers in Kyngäs' study described fear, alongside guilt, worry and depression in connection to their illness. Fear in this and other work is raised by young people in relation to the danger of death from low blood sugar levels and future complications, especially fear of kidney disease, or foot amputation because of circulatory problems (Standiford et al. 1997; Kyngäs & Barlow 1995); and depression in relation to the relentlessness of the regimen and the limitations associated with it (Kyngäs & Barlow 1995). Concern about mortality is also raised by young people with asthma (Rydstrom et al. 1999; Chadwick 1996; Clarke 1992). Findings from one study with 6-18 year-old young people in the USA have indicated that this may be a particularly strong stress for young people with African ethnicity (Yoos & McMullen 1996). In another study, teenage participants were provided with video cameras to record their day-to-day experiences. Authors describe the panic and helplessness apparent in one young woman's film of herself struggling to breathe (Rich & Chalfen 1999). However, findings from work with young people in West London suggest that fear may diminish as young people's experience of managing the illness grows (Gabe et al. 2002), though 8 – 16 year-olds in a study with young people with a range of long-term illnesses describe seeking support more for stress than for the illness itself (Ellerton et al. 1996).

In a study with Swedish children and teenagers with asthma, young people recount feeling guilty about their illness because of the limitations and stresses it places on other family members (Rydstrom et al. 1999). In several different studies with teenagers with sickle cell disorder (SCD) and diabetes, respectively, young people also describe feelings of guilt, here arising out of neglect of self-care, these in turn arising out of feeling unable to maintain the treatment regimen because of its relentless and restrictive nature, and the social impact of this at a time in young people's lives when they are seeking increasing independence (Atkin & Ahmad 2000; Kyngäs & Hentinen 1995). Young people in these and other studies report lying to health care staff and parents as a way of side-stepping the strictness of the regimen (Atkin & Ahmad 2000; Fox 1995; Kyngäs & Barlow 1995). Atkin describes young people's relationship with their illness and intervention as constantly shifting as they are daily caught up in a battle between knowing and wanting to harness the benefits of interventions, while at the same time seeking to minimise the disruption, especially social disruption, caused to their lives; observations which also hold true of accounts of young people's management of diabetes and asthma (Buchbinder et al. 2005; Rydstrom et al. 1999; Kyngäs & Hentinen 1995).

2.5.6 Interaction with clinicians

Children are doubly disempowered in relation to clinicians – both as patients, and as children (Tates & Meeuwesen 2001). Some of the earliest – and most recent - research into children's roles in clinical contexts notes their exclusion from parent/doctor interaction, save for perhaps greetings or farewells (Davis 1982; Strong 1979) and some jokey asides by which the clinician aims to establish a personal relationship with the child and demonstrate empathy (Tates & Meeuwesen 2001). Alan Davis (Davis 1982) attributes this to children's lack of 'basic skills' for interaction rather than adults' exclusion of children. However Philip Strong's extensive observation of paediatric outpatient clinics in both Scotland and the USA identified a pattern of interaction between doctors and mothers - (it was mostly mothers who accompanied children to the clinic) . These recurred almost without exception across both settings, so that children were 'routinely and smoothly excluded from the bulk of the action' both by mothers and doctors (Strong 1979, p 9). Doctors' interaction with mothers was governed by an unquestioned (at least face-to-face) assumption that every mother was a good mother, who would, without fail, take interest in her child's health and follow good advice to that end. Doctors employed a polite rather than aggressive tone (even when this was clearly difficult for them to maintain). Only mothers of 'grossly abnormal' (sic -Strong 1979, p 58) children could be allowed to depart from the ideal, and admit difficulty coping. Thus to win an understanding or sympathy for the difficulties of her situation, a mother had to sacrifice the good name of her child.

Strong found that the relatively few fathers observed in the clinic were treated as incompetent substitutes with questionable knowledge of their child - though unlike mothers, their moral stature was never in doubt. The competence of grandmothers was unquestioned, though like fathers, staff were unconvinced of their ability to provide accurate information when they accompanied the child to the clinic. The fact of anyone else - aside from fathers or grandmothers - accompanying the child to clinic in lieu of the mother was regarded by staff as a failure of parental duty (Strong 1979).

Strong identified a second process of idealisation consistent across settings: that of the expertise of the doctor. This was assumed to rest not on the doctor's individual characteristics but on his or her (mainly his) belonging to an expert profession. Strong notes a doctor's use of the first person plural in giving his opinion. Though the number of errors that came to light on the ward-round was remarkable, Strong found discussion of errors in clinic to be non-existent. Avoidance was a key strategy whereby doctors maintained the image of the infallibility of their expertise.

The third aspect of the clinical encounter identified by Strong was the imbalance of power (Strong 1979). Mothers were allowed to raise minor criticisms and questions, but themselves colluded in a veto on outright challenge. One mother who expressed great dissatisfaction outside of the clinic, once face-to-face with the doctor showed reluctance to set out her position. It was only via prompts from the doctor that she gradually revealed her discontent. In the few instances that parents openly, and without invitation, challenged the doctor's expertise with their own version of the medical situation, their efforts were quickly quashed by staff, even mocked. Michael Bloor's work (Bloor & Horobin 1975) in this area has highlighted a conflict in the doctor-patient relationship: that patients' are expected to use their own judgement to decide when to consult the doctor, but then expected to defer to the doctor's judgement when undergoing treatment.

Strong's (1979) findings of adult exclusion of children from clinical interaction is supported by findings from a 2001 review of doctor-parent-child communication (Tates & Meeuwesen 2001), though studies in this review suggest that as children get older they manage to contribute more to the consultation. Results from this work suggest that where children do succeed in having more of a say, this is usually the result of multiple initiatives on their part, alongside efforts by the clinician to include them to a greater extent (Tates & Meeuwesen 2001).

In more recent work Bridget Young and colleagues (Young et al. 2003) found that young people themselves (in this case 8-17 year-olds being treated for cancer) report feeling marginalised in consultations with doctors. They did not see themselves having direct access to information from health professionals. Rather parents tended to act in an information management role, controlling what and how children learn about their illness. Some children, in some contexts, found this useful. However others were less happy when parents were unwilling or unable to pass on information from the doctor. Children's desire to have more or less information did not seem to be related to age, with some of the youngest children wanting the most detail. Authors conclude that, just as Strong found nearly 30 years ago, consultations are routinely carried out between parents and professionals and children are left without a voice.

2.6 Comparison of knowledge about children and adults' experiences of long-term illness

I want to end this chapter with a brief overview of the differences between what we know about children and young people's experiences of long-term illness and those of adults. It seems that while the physical impact of the illness is increasing recognised in accounts across generations, it has particular importance for children, especially young children because this is also a way that children understand illness; though children clearly develop bio-medical ways of understanding as well.

Psychosocial disruption appears to be a major factor across generations, though in the literature about young people's management it is teenagers' experiences that stand out here, since tensions around the joint management of illness alongside parents and clinicians are reported as especially difficult at a time when young people are striving to establish independent identities.

Description of disruption to resources for children with long-term illness is unsurprisingly absent compared with accounts of adult long-term illness, given that young people do not tend to be the main income earners in families, though, as I have already observed, the financial impact of childhood disability on families has been well documented (Sloper & Beresford 2006).

None of children and young people's responses to the disruption caused to their lives seem to differ markedly from accounts of adult responses, with the importance of asserting sameness and normality apparent across generations. Differences seem to arise mainly out of particular tensions around children's sharing responsibility for care with adults; and, the impact of children's low social status, both specifically within interactions with clinicians, and more generally around how adult ideas about childhood incompetence, particularly outside domestic settings, mean that the necessary competencies of children with long-term illness seem to set them apart from peers.

Most studies seem to have been undertaken from the viewpoint of children's competencies as not 'less' than adults (James et al. 1998), though, on the whole within this sociological and anthropological work, there is little exploration of the impact of children's competencies being different from those of adults. This may be related to the fact that most material does not include the experiences of younger children, where differences in competencies across generations are particularly marked, or concern on the part of authors that discussion of difference might be misinterpreted as underestimating children's understandings of and impact on their care.

There also seems to be relatively little material which includes the experiences of children from ethnic minorities. Further, it is interesting that, given what we know about the impact of social exclusion on the health of those from ethnic minorities, in few instances do authors relate children's experiences of their illness to their ethnicity (Atkin & Ahmad 2000; Yoos & McMullen 1996).

The next part of the thesis sets out the methods I used to collect, assess and synthesise the data for this study. In the following chapter I describe how I drew on methods from systematic review to collect data from previous research studies of younger children's experiences of long-term illness.

Chapter 3: Methods for fieldwork data collection and analysis

In this chapter I describe the methods I used to carry out fieldwork data collection and analysis. In some places the chapter also contains small pieces of information about findings and reflections on methods, since sometimes it seemed more sensible to report these in context, as they arose in relation to the methods. There is a more extensive section reflecting on methods in the final chapter.

3.1 Stages of the study

This study aimed to identify and understand levers and barriers to patient-centred care in multi-cultural settings with children living with long-term illness. I set about this by carrying out:

1. A review - using methods from systematic review - of previous studies to identify data on the experiences, understandings, practices and preferences of children with type 1 diabetes, and children with asthma, in managing their illness alongside families and health professionals

2. In-depth qualitative fieldwork, drawing on methods from ethnography, to explore the experiences, understandings, practices and preferences of children in East London in managing their type 1 diabetes alongside families and health professionals

3. An analysis of data from the fieldwork to produce a report on children's experiences of diabetes in East London

4. A synthesis of findings from the fieldwork and review studies which
    i) set out key aspects of patient-centred care for children with long-term illness

ii) from this, identified barriers and levers to the achievement of patient-centred care for children with long-term illness
iii) included a comparison of the experiences of children across illnesses, ethnicities and ages to inform judgements about the extent to which findings might be generalisable across different populations

This list shows the order in which I carried out stages of the study: fieldwork data collection and analysis took place between collection and analysis of pre-existing data. I want to be clear about this because it had an impact on findings, which I discuss in the conclusions section. However, for the sake of clarity, I will describe my methods for both fieldwork data collection and fieldwork data analysis in this first methods chapter, and my methods for pre-existing data collection and analysis in the next.

3.2 Fieldwork aim and methods

The aim of fieldwork was to explore children's experiences of managing their type 1 diabetes, alongside their carers and health professionals. Qualitative research methods provide us with tools for exploring people's understandings of the world (Pope & Mays 2000). I used a range of qualitative methods (described in more detail in section 3.13) as follows:

- Between two and four interviews/observations with each child, using play-based methods where appropriate, mainly at their home (though a few preferred to meet at the outpatients clinic),
- observation of at least one clinic appointment for each child
- observations in clinic waiting rooms (45 hours)
- discussion groups with children where I fed back my understandings of what I had learned from them, and, in turn, heard their comments on this.

3.3 Doing research with children

Commentators have pointed out how issues at stake when adults research children are not dissimilar to those that arise when adults research other adults (Christensen 2004; Christensen & Prout 2002). It is more a question of how some issues present themselves differently, or "more sharply" in research with children, particularly younger children (O'Kane 2000, p 136) because of their position on the life-course relative to the adult researcher. The single most important of these is the socially produced power differential between adults and children in our culture (Christensen 2004; Christensen & Prout 2002; Punch 2002; Harden et al. 2000; O'Kane 2000; France A et al. 1999; Mayall 1999; Thomas & O'Kane 1998; Alderson & Goodey 1996; Morrow & Richards 1996; Tammivaara & Scott Enright 1986). The second key issue is the impact of children's competencies being different from those of adults, particularly around use of language and ways of communicating (Punch 2002; Woodhead & Faulkner 2001). These issues have implications for many aspects of the design of the research study, as I will describe in the following sections.

3.4 Access

As I have already described, in 2003 I had been fortunate to have the opportunity to assist colleagues at the Institute of Education, University of London with an exploratory, qualitative study of children's experiences and understandings of their type 1 diabetes (Alderson et al. 2006b). Most fieldwork for this was carried out in areas with populations of predominately White ethnic background. In order to ensure the sample included children with a diversity of ethnicities, I was asked to carry out interviews with children and parents at a paediatric diabetes clinic in Newham. It was through this work that I met the consultant endocrinologist who ran the clinic there and a second clinic in Tower Hamlets.

In December 2004 I sent details of the fieldwork for this, my doctorate study; to the consultant and spoke about it on the telephone with the paediatric Diabetes Specialist Nurse in each of the two clinics. The following month the consultant kindly agreed to help me recruit participants for the study from the children in his clinics. At the end of 2006, a new consultant took over responsibility for the Newham clinic. He was supportive of the study and took a positive interest in its progress.

3.5 Sample frame

Participants were recruited from the population of approximately 140 children aged under 11 years on 1 October 2005 being treated for type 1 diabetes in the two East London clinics. In light of Alderson and Morrow's concerns that some groups of children are excluded from research because of having speech or learning disabilities (Alderson & Morrow 2004), I was explicit with staff who sent out letters of invitation that children with learning disabilities or other co-morbidities within this sample frame be included. I have previous experience working with children with speech and learning disabilities and felt competent to modify the research process to meet special needs if necessary.

3.6 Ethics committee approval

I began work on the ethics committee application for the study in November 2004 and received approval from the East London & the City Health Authority Local Research Ethics Committee the following September. I already had experience applying to an ethics committee for approval for a qualitative research project with young people, and had a positive attitude to the potential contribution of ethics committees to research. However, I was anxious that members of the ethics committee would be more concerned with protecting children from potentially negative experiences in research, than promoting opportunities to hear their views. To this end I devoted much of the application to asserting children's rights to commenting on services they receive (see Chapter 1) and to demonstrating the steps I took to ensure that their experience of the research was as positive as it could be; this included supplying copies of the different information materials I produced for parents and for children, and a draft copy of the schedule I planned to use as a guide to my questions in visits with children. I was asked to present the application to the committee in August 2005. In the event, most queries from committee members centred around provision of information for adults: specifically that I produce an information leaflet about the work also for clinical staff; and that all adult information leaflets contain a standard indemnity disclaimer.

3.7 Collaboration with stakeholders

I invited key stakeholders in Barts and the London Trust including representatives from Children's Nursing, Diabetes services, the Children's Forum and the Patient Advice and Liaison Service (PALS) to a seminar in January 2006 in which I presented an outline of my plans for the study, what I had achieved so far, and requested feedback on stakeholders' priorities for the work. Attendees expressed interest in the study though did not raise any specific issues they wished to be addressed. I published a summary of planned work in the School of Nursing EBulletin, which was circulated to about 500 contacts within the Trust; and within this, emphasised the importance of staff input on the planning and outcomes for the work in order to ensure its relevance and contribution to national policy and practice.

3.8 Preparation of information materials

In line with ideas about the importance of children's 'conceptual autonomy' - their being at the true centre of studies of childhood (Qvortrup 1994) – I saw children, not their carers, as the central participants in this study, and as such prepared information leaflets about the work specifically for them (see Appendix 1). My decisions about what to include in these were informed by Alderson and Morrow's useful framework on what children should know in order to give meaningful consent to a research study (Alderson & Morrow

2004). I introduced myself, and included a photograph of myself so children would know what I looked like; I described what would be involved in taking part in the study and that I would like to tape record my visits. I set out limitations to confidentiality afforded (see section on child protection below). I explained what would happen to information provided and emphasised that children could stop taking part at any point. I explained that if someone felt sad as a result of talking about their diabetes, I could put them in touch with someone who might be able to offer support and included details of whom to contact to make a complaint if necessary. I described how I would feed back findings from the study in the discussion groups and via a summary leaflet, offered provision of an interpreter, and set out my contact details.

My assumption in this study, as I set out in the Introduction, is that while I view children's competencies as neither 'less' than those of adults, nor homogenous, I do see them, as, to some extent, different from those of adults, in particular around ways of communicating (Thomas & O'Kane 1998) and this had implications for my approaches to communicating information about the study. While it may not be a common experience for adults to be asked whether or not they want to take part in a research project, it is a relatively common event for adults across a range of populations to be presented with a 'block' of information (either written or verbal), such as the one above, and asked to make a decision on the basis of it. This is less likely to be so for young children in the UK, whose decision-making outside the domestic realm remains limited (Mayall 1996). However, it is more commonly children's experience to read, or be read, a story with an adult and then discuss it afterwards. For this reason, I designed children's information material as A4 leaflets folded in half to A5 size, with the title on the front 'cover', and simple, clear language, with related pictures, inside. My hope was that these to some extent seemed similar to story books that children may have read with - or had read to them by - adults, and that as such, they would find them more useful than conventional research information materials. I had hoped that while younger children and parents used the leaflets together, they would be equally appealing, in style and imagery, to older children who would be able to read them themselves, and I was happy to see children doing this in the clinics when I handed them out.

I also prepared information leaflets for carers containing the same information as those for children but in a more conventional A4 format, without pictures or photographs; and, as already described, at the request of the ethics committee, I prepared information leaflets for clinic staff, which I passed to them, for reference, when I introduced myself at the two clinics.

I consulted with clinic staff to ascertain the languages other than English used by children in the sample frame. These were identified as Somali, Swahili, Urdu, Gujarati, Hindi, Bengali, Turkish, Portuguese and Russian. I arranged that information leaflets for children and carers, and letters of invitation be translated into these languages. Further, in the course of the research I met the mother of a potential participant who took up my offer of having information translated into Polish. In the information material I made clear that though I spoke only English, I could arrange for an interpreter to accompany me on visits, and I included a tick box to request this on the reply slip.

3.9 Privacy and confidentiality

In their book on ethical issues arising in research with children (Alderson & Morrow 2004), Alderson and Morrow raise a range of questions around how children's privacy and confidentiality will be maintained - such as how the researcher obtains children's names, how personal details are changed or stored to maintain anonymity, who will see records and how these will be stored, and whether provisos around child protection may need to be given in relation to guarantees of anonymity - and these formed my framework for thinking about these issues in this work.

Rather than obtaining children's names and contact details from clinical staff, I arranged that, as is described in the following section on recruitment, staff send out information about the project on my behalf including reply-slips with my address and contact details. This meant that I only came to know families' contact details if they provided them directly to me themselves.

In line with practice in previous studies with children (Alderson et al. 2006a), participants chose a code name; some chose their own first name. This was the only identifying characteristic stored on computer next to transcriptions of recordings of my visits with children. All other identifying and demographic information was stored in locked filing cabinets as hard copy only and viewed only by me – as were my fieldwork notes. While hiding their identity may have been important to some children, others seemed keen for their identity to be known. The mechanism of choosing a code name is designed to give children some control over this, although because participants cannot know the ultimate context in which their words and behaviour will be presented, I decided that I would not use participants' surnames in the study, even if they requested this (Giordano et al. 2007).

In the information leaflets for children and carers, I explained that I would guarantee participants' anonymity in all circumstances except where I became concerned about their or someone else's safety. Appendix 2 describes the protocol I would follow if this happened, (which it did not). I also explained this limitation to my guarantee of anonymity to participants in person, though I found this very difficult to do as it necessarily implies a lack of trust in carers' ability to protect their children, or worse that they might be harming them. I often found myself presenting this with the caveat that 'this is what I have to say to everyone'. My discomfort reminded me of Strong's study of doctors' interaction with mothers, where he identified a powerful social taboo around any suggestion of mothers' less than perfect parenting skills (Strong 1979).

As well as drawing up a protocol around issues of children's protection, I also developed one around ensuring my own safety during fieldwork (Appendix 3).

3.10 Recruitment

In October 2005 I was ready to begin recruitment for the fieldwork. I sent the consultant draft letters of invitation for children and their parents, reply slips, information leaflets (one for carers and one for children) and SAEs, in the 10 different languages which the Diabetes Specialist Nurses had identified as likely to be relevant for this population. The consultant arranged that the invitations (see Appendix 4) be printed out on hospital headed paper both in English and, where necessary, in an additional language, signed from him and sent out with the additional information, reply slips and SAEs to all children within the sample frame. When families made contact, I discussed their questions and then, if they agreed, arranged when and where to meet with them, either at the clinic or at their home. In the smart, newly built community health centre in Newham, there was a spacious and comfortable meeting room which clinic staff were kind enough to let me borrow at certain times of the week. A spare room was harder to find at the hospital where the Tower Hamlets clinic was held, though occasionally a small consulting room, leading directly off the main waiting room, was available.

It is well-established that, in light of the disparities in power between researcher and researched (particularly in research across generations) it is important to ensure that researchers do not pressurise potential participants into agreeing to take part against their better judgement (Alderson & Morrow 2004). Equally, I would like to argue, researchers have a duty to present themselves and their research in such a way that is attractive and accessible to potential participants in order to ensure they are not excluding anyone from taking part in research (Alderson & Morrow 2004). While it may be argued that for the most part benefits to individuals of taking part in research studies remain negligible, routine (though inadvertent) exclusion of certain groups - for example, people from minority ethnic groups from studies of stakeholder views, or trials of new interventions – is clearly problematic. For these reasons I was concerned when one of the paediatric Diabetes Specialist Nurses expressed concern to me that receiving only a formal, written invitation to participate in the study would be off-putting to many of the families who attend her clinic. Her experience of working with these families was that in order to be accessible, invitations would also have to be offered verbally, face-to-face, in clinic. So, as well as sending out written invitations, between 26th October 2005 and 1st March 2006, I spent 12 mornings/afternoons in paediatric diabetes clinic waiting rooms. Here I approached potential participants, both adult(s) and child, in a quiet but friendly manner, usually stooping to be on a level with them as they sat in waiting room chairs. I briefly introduced myself, saying I was doing a project to find out what children think about their diabetes, and then handed out the information leaflet which I explained would tell them more, indicating that the leaflet for young children was designed for them to look at alongside their parents.

3.11 Consent

As part of putting children at the centre of the study (Qvortrup 1994), I was keen that, as much as possible, children be the main deciders about their participation in the study. To this end I adopted the following strategies:

- (as already described), I produced information materials about the study specifically designed for children;
- I arranged that written invitations cite the child's name before that of the parent;
- I tried to ensure that when I approached families in clinic, it was when children and parents were together, so that I could look at the child as well as adults when describing the study and hand an information leaflet to each
- *If parents seemed to indicate interest in participation without recourse* to their child, I reserved my own judgements about children's decision until I had had a chance to check this myself in my first visit *with them*

- In my interactions with children during home and clinic visits I made clear it was their (on-going) consent that determined their continuation at different stages in the study.

However, because of parents' practical and legal control over children's lives, it would be undesirable for a child to take part against their parents' will. To this extent, consent was necessary both from children and from parents, and I reflected this in my design of the written consent form, which required 'signatures' from both the child and parent. I decided to opt for written consent from both children and parent since, where children were less familiar with the idea of making a mark to signify their agreement, I simply asked them for a verbal response as to whether or not they wanted to take part, and if they did, explained that I would like them to make a mark on the form to show their agreement.

My model for thinking about children's consent to participation was based on that in The Nuremburg Code developed in the aftermath of the Second World War (Office for Human Subjects Research website 2008). While this was developed in relation to clinical research, it can be interpreted in such as way as to provide a framework for a study such as this. The code sets out the importance that consent be voluntary - specifically that the potential participant (child) should:

- have legal capacity to give consent
- should be so situated as to be able to exercise free power of choice, without the intervention of any element of force … and during the course of the work, be at liberty to bring the study to an end
- and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.

Remaining sections mainly concern protection of participants from negative consequences of participation, understood in this context as:

- the study should be carried out in a way that avoids unnecessary distress to participants, that the degree of risk of this should not outweigh the potential usefulness of findings, and that provision should be made to protect participants from this
- the researcher should be sufficiently qualified to carry out the work.

I deal with each of these points individually, below.

3.11.1 Legal capacity

I was guided in terms of the legality of children's consent by the precedent set in the case Gillick v W Norfolk and Wisbech AHA (Gillick v West Norfolk and Wisbech AHA 1984) – specifically :

> As a matter of law, the parental right to determine whether or not their minor child will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to understand fully what is proposed.
>
> Gillick v W Norfolk and Wisbech AHA (1985) 3 All ER 434

This then relates to point 3.11.3 below, about children's sufficient comprehension.

3.11.2 Free power of choice and option to end participation

There is an imbalance of power when professional researchers approach adults in a lay capacity and as receivers of health care services to take part in research studies, and for this reason ethics committees exert considerable influence to ensure that researchers do not pressurise potential participants into agreeing to take part and also that they make clear to potential participants that the decision to take part should be freely given. Because of the disparity between adult and child status, this imbalance of power is multiplied when an adult researcher approaches a potential participant who is a child. To mitigate this, I took a number of steps to ensure that children did not feel pressurised into taking part:

a) Opt in

One model for consent, particularly in studies undertaken in institutions, is for researchers to approach gatekeepers who control access to participants for permission to undertake research with all individuals within that institution, except for those that specifically 'opt out' of the study by actively saying they do not want to take part. However, it seems to put less pressure on participants to take part if the model is an 'opt-in' one, where people have to actively say if they do want to participate, and the default position is that unless they do this, they will not take part (Alderson & Morrow 2004). This last model is the one I used in this study: I assumed potential participants did not want to take part unless they actively said that they did.

Secondly I made clear in invitations, information materials and in face-to-face discussions with children and carers that I did not mind if they decided not to take part. I was explicit about the fact that their decision would not affect their health care.

b) Gatekeepers

I discuss later the potential problem of parental gate keeping barring children from taking part in a study regardless of children's own preferences; however, equally, gatekeepers' enthusiasm to promote participation in a study can be a problem. I have found this may be particularly so in research with young people (Curtis et al. 2004b), although because of the degree of control I retained over my approaches to children and their families, I did not anticipate that this would be a problem in this study. However, in one instance, when I was carrying out observations in the clinic waiting room, a well-meaning nurse brought a young boy and his mother over to meet me and to encourage them to take part in the study. I had to explain to the boy and his mother, and to the nurse, that although I appreciated her trying to support my work, I really wanted potential participants to make their own decisions about whether or not to take part and did not want them to feel pressured in any way. In the event, neither the boy nor his mother wanted to participate and seemed quite comfortable about being clear about this.

c) *On-going consent*

I made clear to children in information materials and face-to-face discussions that their giving consent was not a one-off event, but that they could withdraw this at any point in the study: I would not mind and it would not affect their health care. Further I made clear that if I asked them a question they did not want to answer they could just tell me; we would move onto another question and I would not ask them why. To some extent I have concerns that being explicit about this last point is patronising, since in previous research it has seemed that most children are readily able to fend off questions they are not comfortable to answer by saying "I don't know" or changing the subject; however, it may be that this is not the case with all children.

I also watched children for non-verbal signs of their withdrawing consent, such as lack of engagement with me or processes of the research, and used these as a prompt for asking if they were sure they still wanted to continue. Because of the social pressure on all people, children and adults, to finish projects once they are embarked upon, and how this is multiplied for children taking part in adult-led research, I try to couch any potential decision to cease participation in as positive terms as possible. My reflections on use of this mechanism in fieldwork raised several issues which I discuss further in the section on my role as researcher.

I double-checked children's verbal consent to observe their appointment with clinicians both prior to and on the day of their appointment. In one instance I was late for the appointment and failed to do this. The child did not want to give retrospective consent, so, although her sister, who had accompanied her, insisted that it was fine for me to have observed, I withdrew my notes from the analysis. One other participant, George, did not want me to observe his appointment as he was concerned he would be having his annual blood test, about which he was extremely nervous.

d) Written and oral invitations

As I described already, participants were recruited both by written and oral invitation in order to ensure that - while no pressure was put on people to take part - invitations were as appropriate and accessible to potential participants as possible.

e) Time to decide

I was concerned that face-to-face invitations would put pressure on people to make an on-the-spot decision about taking part. In order to avoid this, when people said they definitely did want to take part, or were not sure, I offered to telephone them in a week's time to check whether they wanted to participate. Most people who had already decided to take part did not take up this option, however several who were unsure did. I summarise recruitment and responses to it in the section on fieldwork reflections in the Conclusions chapter.

3.11.3 Sufficient knowledge and comprehension

The third condition for consent in the Nuremberg model is sufficient knowledge and comprehension, which, as I described in the section on legal capacity to consent, is, according to the precedent set in the Gillick ruling (Gillick v West Norfolk and Wisbech AHA 1984), also the condition for children's legal participation in this country. In some cases carers decided that children would not take part, without recourse to the child's opinion, perhaps because they did not think the child understood enough about what would be involved in participating. However, where this did not happen, the decision about whether or not they had sufficient comprehension of what was involved was made by me. In order to facilitate children's understandings I took the following steps:

a) Provision of accessible information materials: as described above

b) Reminders about key aspects of research: On my first fieldwork visit with children I went through the information leaflets with them again, before asking if they wanted to sign the consent form, in which key aspects of involvement were once again re-iterated. In subsequent visits, I reminded children verbally that they would be in charge of what they said, and could ask to stop at any time; that there would be no right answers, I would just like to hear what they think (Punch 2002); that I would want to make a tape of what they say, but they that would have a code name to keep their real name secret if they wanted; that if they would like to do any drawings I would like to keep them if they were happy with that (I would return them later); and that I would want to put what they told me and showed me into a book to show other grown-ups. I made an A4 pictorial prompt sheet with an image relating to each of these items which I used with some of the younger children.

c) Opportunity for questions

When I first talked with families about the study, and again at the beginning of each visit I asked children if they had any questions about the work.

d) Support from carers facilitating children's comprehension

As described I designed information materials in such a way as to facilitate carers and, in particular, younger children, looking at them together, in order to provide opportunities for carers to support children's understandings of what would be involved in participation.

e) The friendly stranger role

Although I judged all children to have sufficient comprehension to consent (or not) to direct engagement in the research, I was less sure that the very youngest, for example, pre-school, children retained understanding that what they told or showed me would be 'put in a book to show people who plan health services' . However, because I met with most of them only twice at home and about twice at the clinic, I believe that, particularly with the very youngest children, for whom even a month gap between visits could seem a long time, I remained largely unfamiliar, albeit - I hope – approachable and friendly. I felt that this discouraged children from revealing anything to me that they would not have been happy to reveal to a wider, benign, adult audience.

3.11.4 Avoiding distress

The remaining items of the Nuremberg Code focus on the prevention of suffering and death of participants, which in this context I have interpreted as the prevention of distress to participants. This includes the stipulation that no research should be carried out that puts the participants in danger of death or disabling injury; that the degree of risk of suffering should not outweigh the potential usefulness of findings; that there should be provision to protect participants from suffering; and that the researcher should be willing to halt proceedings if necessary. I acknowledged in the information materials for children and for their carers that, sometimes, talking about one's life can be upsetting, and that participants could move to a different question or cease participation as they wished. We know that children can experience research as intrusive (Edwards & Alldred 1999), so I aimed to minimise the risk of this by being sensitive to the pace and cues of participants as much as possible in our interaction, and offering opportunities to move on from a subject if they wished.

My experience in this and previous work is that many children – and particularly younger, and so supposedly more vulnerable, children - are extremely adept at managing situations in which they are not comfortable: either spontaneously changing the subject, saying 'I don't know' or not answering at all. I discuss below how provision of games and toys proved useful not just as prompts for discussion of children's lives, but also as distractions to which children turned when they wished to move on from or avoid a question. This was not just something I noticed: one carer also observed how Keith – a participant whose background was such that he might easily be gauged a particularly vulnerable child – was adroit in avoiding or ignoring my questions as he wished.

I also carried with me details of support and information services for families should they require these. One mother took details of a local support group for families with a diabetic child, and another details of the Diabetes UK Careline, where information and support can be accessed in a range of different languages.

3.11.5 The researcher should be sufficiently qualified to carry out the work

The final part of the code includes an item stipulating the importance of the researcher being sufficiently qualified to carry out the study. In my case I had been carrying out consultation and qualitative research projects with children across a range of ages and backgrounds for five years prior to starting this work. While I undoubtedly learned a considerable amount in the course of this study, I feel that I had sufficient experience at the beginning to ensure that taking part was as positive an experience as it could be.

3.12 My role as researcher

As an adult from a middle class and majority ethnic background, working mainly with children from less affluent and minority ethnic backgrounds, I also tried to abandon internal assumptions about having superior knowledge and understanding of children lives (Alderson & Goodey 1996). I tried to be open to children's agendas (Thomas & O'Kane 1998), both during fieldwork and analysis (Punch 2002; Mayall 1999; Thomas & O'Kane 1998) in order to recognise the particular expertise which individuals have about their own lives (Roberts et al. 1993). Christensen has described how in her ethnographic research with children such openness required her rejecting the 'traditional' adult role of 'protecting or looking after' children (Christensen 2004, p174). This last endeavour I found increasingly difficult as the study progressed. I discuss this further in the Conclusions chapter.

Some commentators have stressed the importance of ensuring that researcher and researched share the same ethnic background, though this was not a model I chose in the design of this study. On a practical level, it would have rendered it a very different piece of work, employing at least six different interviewers to 'match' the sample recruited - though potentially many more, given the ethnic diversity of the population - and as such costing much more than could be funded via the studentship award. Yet, I did have a particular concern that most children in the study were likely to have come across people with similar demographic characteristics as me in school or pre-school settings, where the status of children may be low compared with adults (Mayall 1996). To counter this, I used the techniques set out below.

As I have already described, I tried to directly communicate to children that, unlike in most interaction with adults, I did not expect them to say what they thought I wanted to hear (Punch 2002). In past research with children, I have found it useful to present myself as what Lofland and Lofland describe as 'the acceptable incompetent' (Lofland & Lofland 1995): that is, someone with little comprehension of the topics under discussion, who therefore defers to participants for guidance and understanding. I also found this a useful approach at the start of this study, but as the work unfolded, and I became more and more familiar with the details of children's lives in managing their diabetes – or to borrow from grounded theory, as fewer new accounts of children's experiences emerged, and I reached 'saturation' (Glaser 1992) I began to feel such an approach to be disingenuous. Once I felt this, it no longer seemed to me to be viable, since I was concerned children would sense my discomfort and feel patronised - although I have no way of knowing whether or not this was actually the case. When this happened, my default position was to try to be as 'nonthreatening' (Lofland & Lofland 1995, p 55) as possible by showing interest in and sympathy with what children told or showed me about their diabetes. I should add, however, that the differences between social and generational aspects of my own and many participants' backgrounds made maintenance of the 'acceptable incompetent' role much more appropriate in some other 'non-diabetes' related aspects of children's lives. For example, my ignorance about 'Subuteo', Nintendo, and the scoring system of the football premier league was genuine, and I relied on children to enlighten me about these.

Mayall reports that children she has worked with invariably see power over children as a central characteristic of adulthood, and therefore the challenge for the researcher is to create, within this, space for hearing children's views (Mayall 2001). Christensen gives some indication of how this might be done, when she observes how power does not absolutely reside in positions such as 'adult' and 'child' but is rather designated via interaction, such as demonstrating a continuous commitment to attentive listening regardless of outside interruption (Christensen 2004). Likewise, Myra Bluebond-Langer describes how, in her extensive hospital-based fieldwork, she demonstrated via small gestures the more negotiated relationship she wished to establish with children. For example, she always asked a child's permission before entering his or her room, not common practice by adults in the clinical setting in which she was meeting with children (Bluebond-Langner 1978). I used the same approach to communicate my desire to reduce the difference between my and children's social status in my interaction with them, for example, asking children's permission before I sat next to them in the clinic waiting room, and re-checking with them (rather than their carers), on the day of their appointment with the consultant, their permission for me to observe this. When meeting children in the private space of their homes, it was even easier to find opportunities to ask children to take the lead, for example, asking where I should sit, how long I should visit in light of any other plans they might have for the day, and whether they wanted me to come back for a further visit.

However, it would be misleading to claim that children were entirely 'in charge' during fieldwork. I retained power over the boundaries of our interaction to the extent that though children sometimes wanted to explore other aspects of their lives or engage in non-diabetes related activities, after some time I invariably brought the interaction back to a diabetes focus. Carers' agendas sometimes set parameters - for example, my first meeting with Shadow was cut short because his mother had made plans to meet friends to go shopping. Finally, children's homes are also their carers' homes and because of this I felt I could not entirely overrule some of carers' expectations of me as an adult: for example, in one instance, a game with children, siblings and their friends began to get particularly rowdy when the carer was out of the room, and I found myself asking children to play more gently, responding to carers' expectations that I remain in charge, and responsible for children not damaging the space or each other. My role was, therefore, closer to Mayall's model of seeking space for hearing children within an adult role (Mayall 2001), as opposed to seeking to entirely remake the adult/child relationship, in particular via rejection of the 'traditional' adult role of 'protecting or looking after' children as Christensen suggests (Christensen 2004, p 174).

Punch suggests that communicating openness to children's agendas is much easier once a trusting relationship has been built between researcher and participants (Punch 2002). Certainly I found that meeting children over several occasions – between four and seven times depending on the participant - was a great help in building rapport. However, I was also concerned - though I may have been wrong - that the very young children in the study, those aged 3 and 4 years, did not always retain the fact that I would like to pass onto other adults what they told and showed me about their diabetes. To this extent I felt it was helpful that I remained somewhat a stranger to them since - as I described in the earlier section on consent - it may have ensured they did not reveal anything to me that they would not have revealed to other benevolent, but unfamiliar, adults. Though in some cases this may have excluded me from more private accounts of children's experiences (Cornwell 1984), I was content that such a choice chimed with past decision-making by feminist researchers to focus on the ethics of individual relationships with participants, as opposed to viewing them merely as a data source (Finch 1984; Oakley 1981).

As well as emphasising to children that I really wanted to hear their views, and trying to demonstrate this via my interaction with them, I also invited children's input on the course and conduct of the fieldwork, both to demonstrate my desire for a more negotiated relationship, but also to increase the validity of the fieldwork. I discuss this further at the end of the section on home visits, below.

Although carers were not participants in the work, my interaction with them, as I have already described, impacted on children's involvement in the study, and as such, was important. Here, clearly, differences in adult and child status were not a factor. I shared majority ethnicity, and a professional background, with several - different – parents, though this was not the case with most. In preparation for the study I had planned to present myself as non-threatening to parents across different demographics by appearing interested, polite and sympathetic (Lofland & Lofland 1995), and, as the study progressed, I realised how well this dovetailed with my strong sense of my status as 'guest' in participants' homes. I was particularly conscious that carers – in the event almost without exception, mothers - let me visit children at their homes, while they, in turn, did not have the opportunity to see the state of my home. Though this may not have been the case for the mothers in the study, from my own point of view, this felt revealing and courageous: especially to welcome in someone who – in most cases – was from a more affluent social background. I found myself unconsciously, in conversation, revealing to mothers some of the 'messiness' of my own life; for example, that I had also, recently, become a mother and that, sometimes, I did not find this a particularly easy role. This was a situation where I could revert easily to the 'acceptable incompetent' role (Lofland & Lofland 1995) - the mothers of children in the study invariably had several years experience on me – and draw on some of our shared experiences as women (Oakley 1981).

Finally, this study took place against a backdrop of considerable political tension. Terrorist activities undertaken in the name of Islam, actions of the UK government both at home and elsewhere, and widespread social exclusion of people from ethnic backgrounds where Islam is traditionally practiced have considerably alienated some people – not just Muslims - living in London. I had carried out extensive fieldwork with teenagers in East London two or three years prior to starting this study (Curtis et al. 2005). The political climate was much the same. In neither that nor this current study did I feel that these political issues impacted in any way on the fieldwork of these studies. I do not know whether this was because I managed to communicate sufficient goodwill to families to assuage any suspicions they might have had about the attitudes of someone with my social and ethnic background, or whether they judged that someone doing a study of this type in these areas would be unlikely to hold these kind of views anyway. The only reference made to these events in the course of the work was by one mother, Mrs S, who, in conversation, volunteered how frightened her son had been after the 2005 London bombings. I do not know very much about Mrs S's ethnic, cultural or religious background - she described herself simply as 'British' - but as we sat opposite each other, me pale-skinned, in jeans and trainers, and her, brown-skinned, in a salwar kameez, her comments indicated how events ascribed to one community have a deeper resonance for all Londoners.

3.13 Methods

Commentators recommend that interaction with children in fieldwork should fall in line with children's everyday experiences and interests. For Christensen, an ethnographer, this entails the researcher learning research participants' 'cultures of communication'; that is, observing and trying to learn how participants communicate in order to reflect similar approaches in one's communication with them (Christensen 2004). Such an approach addresses issues both of differential power and of differential experiences, understandings and use of language between researcher and researched; and guards against misleading attachments to 'essentialist' ideas about how 'children', or any other group, communicate. As such it has much in common with other commentators' call for high levels of self-awareness or reflexivity when carrying out research with children (Davis 1998; Punch 2002).

Other researchers have observed children as broadly competent in certain kinds of activities routinely practised in their day-to-day lives, for example, drawing, painting, model making and role-play with toys, and, on the strength of this, recommended their inclusion in research on children's views (Curtis et al. 2004a; Lancaster et al. 2003; Punch 2002; Christensen & James 2001; Bradding & Hortman 1999; Backett & Alexander 1991). Because of their open-ended nature, creative or activity based methods have come to be described as 'participatory': children can influence the content and the pace of interaction, and there tends to be fewer "right" answers, which helps to offset the power imbalance between researcher and researched (Punch 2002; Christensen & James 2001; O'Kane 2000). Commentators suggest that the outputs from such approaches should not be analysed in isolation, but rather used as a stimulus for talk and analysed alongside findings from discussion (Harden et al. 2000; O'Kane C 2000). Certainly it has been my experience in previous work with young children that conversations with young children seem to flow particularly well when the child is also engaged in another activity, such as playing with soft toys or lego - whether or not that activity relates to the subject of conversation. Perhaps this is because this simulates the kind of adult-child interaction with which many young children may be familiar in domestic and pre-school settings. Researchers also warn that of course not all children will feel equally competent and confident across different activities. Offering a selection of activities (Curtis et al. 2004a; Punch 2002) and working with a high degree of reflexivity (Punch 2002; Davis 1998) are both essential.

It is these ideas about methods in research with children that influenced my choices in this study. I describe these in more detail in the sub-sections below.

3.13.1 Home visits

I met with participating children at their homes to carry out activities, ask questions and make observations around their experience of managing their diabetes. This was broadly based around the schedule set out in Appendix 5, although I picked up children's cues from what they said, followed their lead and order of topics, and played games they suggested too. I asked children about the important things in their lives and gave them a camera to photograph these (see section below). I asked them to tell me about what happens in their day, including things they do to look after their diabetes. Younger children showed me what they do using Teddies or dolls and a diabetes kit, which I brought with me (with needles removed). Many children went to get their own kits to show me, or let me watch them doing their finger prick and blood test. I also asked what children remembered about when they were diagnosed. If children wanted, they did drawings of important things in their lives, or things they do to look after their diabetes, which I then discussed with them (Bradding & Hortman 1999; Backett & Alexander 1991). Keith was reluctant to draw as he had had difficulties learning to hold a pen and this was an achievement he had only recently accomplished. I usually asked children who did want to draw if they would mind including a drawing of the diabetes clinic, which I then used as a prompt – along with a toy medical kit for younger children – to talk about their experiences of visiting the clinic. Between visits I double-checked the schedule for anything we had not covered in the first meeting. I then raised this with children in the second meeting, and also discussed their photographs with them (see section below), and played the 'who decides' game, (see point 6 of Interview guide, Appendix 5) which was based on an activity described by Claire O'Kane carried out with children to discuss 'who was having what kind of say about different decisions in the child's life' p 143 (O'Kane 2000). This game was not suitable with pre-school children, whom I asked about the same issues in the course of play with 'Teddy, who has diabetes', or gauged the answers by observing their play. Finally I asked children if they had any "top tips" or things they would tell someone else / Teddy who had just got diabetes in order to help them.

I piloted the schedule in my first three meetings with children, though I included these in the final analysis because activities seemed largely successful as a prompt for exploring children's views. I did, however, omit a question I had included originally about what children would change about their care, if they had one wish. Both children who answered this dismissed it, apparently with great sadness, saying nothing could be changed. After this, I felt uncomfortable routinely including a question of such seeming sensitivity, and decided in future to raise this only if it came up naturally in the course of my interaction with children. Further, I piloted with two siblings, Trunks and Little Miss Perfect, an activity with toy foods, where I asked children to sort foods by what they liked and what they could eat. They – and their cousins who were visiting at the time and joined in – all seemed to enjoy this activity. However, as the research progressed I realised that these two had a particularly positive attitude towards their diabetes care, which other children did not share. I felt that asking children who felt less positive about the regimen to play with toys representing 'forbidden' or restricted foods could be unkind. In one instance, a girl, Lil' Bratz, asked me to play a board game which involved getting a plastic 'ice cream' at the end. I felt doing this was different, since it was Lil' Bratz, not me, who initiated the game.

The schedule worked best when it prompted children to tell me stories, or show me stories through their play, of things that they had done, or had happen to them, around their diabetes. This chimes with observations by other researchers about the power of narratives in exploring people's experiences (Cornwell 1984; Graham 1984). In retrospect, I would not have changed the content of the schedule, but altered some of the prompts to more actively elicit children's stories about their lives.

Most children carried out these activities over two visits that I made to their home, mostly about a month apart, although for five children there was a gap between two and four months between visits. One child, Keith, I visited on four occasions. He was keen to take part, but did not like sustained discussion of his diabetes, preferring to intersperse 'my' activities with activities of his choice, mostly board games and Nintendo. Visits varied in length from 20 minutes to three hours, depending on the preferences of children and their carers. I had explained visits would take about an hour, but twice my visit was cut short after half an hour: on one occasion a large group of visitors arrived and Zak began to feel self-conscious talking in front of them; on another, because Shadow's mother had an alternative engagement.

I tape-recorded visits with children and families. Where children's actions communicated their experiences and understandings - rather than their words - for example in play and games, or when they were demonstrating their use of their diabetes care equipment, I commented out loud on these so that they were recorded for the tape. I transcribed half of the tapes myself, and the remainder were done by a transcriber whose services had been employed in a previous study and whose work had been found to be accurate enough for research purposes. Unfortunately the recording of one short meeting, at a clinic (the 20 minute meeting, described previously), was lost because the tape jammed and broke when it was rewound. I describe the fieldnotes I kept in relation to home visits in the section below on observation.

I incorporated two questions at the end of my final meeting with each child about whether there was anything else we had not discussed which he or she might want to tell me about having diabetes; and also whether he or she would have done the project differently.

3.13.2 Disposable cameras

In order to learn more about children's lives in general and to help understand the degree of significance accorded diabetes in the context of their rest of their life, I gave each child a disposable camera to photograph the important things or people in their lives, and used these photographs as a stimulus for discussion with children (Clark A & Moss 2001; Schratz & Steiner-Loffler 1998). When I gave the child the disposable camera, I showed him or her how the wind-on mechanism worked, and emphasised the importance of using the flash for photographs taken indoors. I encouraged children to have a go taking a first photograph when I was there to help them with any problems they might have. After one child's camera was confiscated by staff at school – presumably worried about protecting the identities of other children in the school - I warned children about potential problems with taking cameras into school. I provided children with a stamped envelope addressed to me in which to return the camera, and took the photographs to be developed when the cameras were sent back to me. I marked the envelope of developed photographs with the child's chosen study code name and did not open this or look at the photographs myself. In my next visit, I passed the child the folder and asked if we could look at the photographs together. As we looked at the photographs I asked children about who or what was in them and why they chose to take those photographs. This approach runs the risk of children being disappointed if their photographs do not come out, but I was lucky that this did not happen in this study.

3.13.3 Observation (both in clinics and homes during visits)

Commentators emphasise the advantages of using different qualitative research methods – in particular interview and observation - alongside one another, (Adler & Adler 2000; Mayall 1999; Lofland & Lofland 1995; West 1990) in order to explore inferences arising from similarities and differences between data from different sources (Hammersley & Atkinson 1992). Alongside discussions with children, home visits provided considerable opportunity for observation of children's experiences of their diabetes care in domestic settings. Because of the privacy normally associated with family life (Harden et al. 2000; Mayall 1999; Prout 1986) and the extent to which I wanted my interactions with children and families to resemble informal 'everyday' human interaction, I decided against on-going conspicuous note-taking in this context and instead made mental notes (Lofland & Lofland 1995) which I then wrote up on the train home. On these journeys I also wrote up a short description of my perception of the general physical environment of children's homes, and any other data I judged relevant that might not have been adequately recorded on the tape. Further, I found it useful to monitor my emotions after the end of a home visit (Lofland & Lofland 1995), and write up the details of any interactions or experiences about which I found I was carrying feelings of unease. I found this to be an exceptionally useful method for monitoring my experiences and reflections on methodology.

As I have already described, I carried out approximately 45 hours of observation in the waiting rooms of the paediatric diabetes clinics. This enable me to familiarise myself with staff and the workings of the clinic, and observe staff and children's use of equipment and space in the waiting room, and children's experiences of waiting for their appointment - often over protracted amounts of time. I began to meet some of the children attending clinics, and brought in pens and paper so they could entertain themselves with drawing during the wait.

In writing fieldnotes on these and other observations I tried to adhere to commentators' recommendations to be as concrete as possible - recording 'at the lowest possible level of inference' (Lofland & Lofland 1995, p 93) – and to distinguish between verbatim accounts from my own précis of people's speech (Lofland & Lofland 1995; Hammersley & Atkinson 1992).

As already described, I asked each participating child if I could observe one of their appointments with the consultant. Fifteen of the 17 children agreed to this, and Shadow agreed to my observing two of his appointments with the consultant and also an appointment with the nutritionist. On these occasions children also agreed for me to observe their visit to the 'blood' nurse, who took a sample of their blood to test for average blood glucose levels over previous weeks, and then weighed and measured the children. I centred my observations primarily on what children were doing and saying in these situations, and then, secondly, on the process and content of interaction involving others. I drew a diagram of where children, staff and families positioned themselves in the appointment with the consultant.

3.13.4 Feedback and discussion groups

Six months after the beginning of fieldwork, I sent children a plain language, attractive looking newsletter summarising interim findings from the study. Two months after that, I invited them to take part in a discussion group to comment on a summary of my early understandings of what they had told me in our meetings. I incorporated their views on these in the final results from the fieldwork. About half the children came to one of two final discussion group meetings where I organised feedback as part of interactive games and activities – for example I put together a pack of A4 photographs illustrating a category of things children had told me were important in their lives – such as pets, family members, activities – and each child took turns to show the group the pictures in their pack and guess to what they related. They told me if they broadly agreed with my interpretations or had other ideas themselves.

I had hoped to be able to book additional rooms where parents could wait while children took part in the groups, but in the event none were available and so both groups were observed by carers seated in chairs around the edge of the room. To some extent, this was helpful, especially for one or two children who felt shy at first and wanted to sit with parents. However, it may have constrained children's expression of their views to take part in the group with an audience of their own and others' carers.

There were five participants in the group held in Tower Hamlets, and six in the Newham group. Usually I would design groups so that children of similar ages and experiences are together. However, with such small numbers it was not possible to divide groups by age. I designed activities to be as appropriate across ages as possible, however the shorter attention span and less experience of group work of the 4 year-old Spiderman meant that he fairly frequently interrupted the discussions of other children in the group, who were mostly about three years older than him.

In January 2007 I sent children a final summary of findings from the study.

3.14 Provision for people who do not use English

In the information material for children and carers I made clear that though I spoke only English, I could arrange for an interpreter to accompany me on visits, and I included a tick box to request this on the reply slip. In the event, perhaps because of their experiences in school and pre-school, all children taking part in the study spoke English; though two parents requested interpreters for their own use: the mother of one participant, Marjan, requested a Somali-speaker, and Girls Aloud's mother, requested a Swahili-speaker.

At the end of my first visit to Marjan's home, her 18 year-old sister requested that in the second visit she act as the interpreter, rather than bringing in an outsider. I was able to arrange payment for her through the language agency in the same way that I would have arranged payment for the outside interpreter. The family had seemed to warm to the first interpreter, but Marjan's sister felt that she could do the job just as well and would appreciate being paid for it, an eventuality which systems at the language agency had been designed to cater for.

I had had experience working with interpreters in a qualitative study of people's experiences of having smoke alarms in their homes (Roberts et al. 2004) and from this had concerns about interpreters' understanding of the importance in research of keeping interpretation as precise as possible. I raised this with the language agency when I booked interpreters, and was assured that all interpreters had a good understanding of this.

3.15 Rewards

Giving participants incentives or rewards is a tricky question in any research setting (Curtis et al. 2004b). In previous work I have found the thank you payment a strong motivator for some young people to take part (Curtis et al. 2004b) – though it is debatable as to whether this is positive or not. However, I did not think motivation based simply on wanting to get a reward would be enough to sustain the on-going involvement requested of participants in this study. So, although I provided participants with a £15 gift voucher for Woolworths at the end of their involvement, along with laminated copies of any pictures they had done, and a certificate which thanked them for their participation, I did not tell them about this at the outset.

I chose Woolworths because it was the shop with the widest selection of toys, relatively local to participants' homes. However, I was also aware that huge displays of sweets are routinely set up near the entrance of this shop, and in having to pass these to get to the toy displays further back, some children might feel sad about the extent to which their diabetes regimen limits their participation in a long-standing ritual of childhood: buying and eating sweets.

3.16 Methods for analysis of fieldwork data

This study comprised a review of qualitative data using methods from systematic review, and an in-depth qualitative fieldwork study. Findings are directly drawn from both primary and secondary data. In this section I describe how I set about analysing data collected in fieldwork.

3.16.1 Familiarisation

I began data analysis via an on-going process of "familiarisation" (Ritchie & Spencer 1994) during fieldwork: reading and re-reading fieldnotes and transcripts, and noting emerging themes and sub-themes.

3.16.2 Extraction and management of data

Fieldwork data comprised:

- transcriptions and observation notes from individual discussions with children
- transcriptions and observation notes from two feedback group discussions (at the end of the study children were invited to a discussion group to hear my views and understandings of what I had learnt from them and to give me feedback on this)
- notes from my observations in clinic waiting rooms and of at least one appointment with clinical staff for each child.

I printed out transcriptions of discussions with wide right-hand margins and photocopied notes from observations onto large sheets of paper to create wide margins. I used the data management software package QSR*Nudist to organise data after initial coding, described below.

3.16.3 Identification of themes via the constant comparative method

I used grounded theory's constant comparative method (Glaser 1992) to identify:

- themes arising directly from the data
- themes arising from other data in this study

- themes suggested by existing theoretical work on children's health and illness, and adults' experiences of long-term illness
- themes relating to the practice aim of this work: to identify levers and barriers to patient-centred care with children

More specifically - and I clarify this to avoid the 'methodological anarchy' sometimes associated with the constant comparative approach (Dixon-Woods et al. 2005a, p 48) I identified themes by 'making constant comparisons of incident to incident' (Glaser 1992, p39) and then, when main themes began to emerge, incident to category to generate sub-themes. I was also careful to identify negative cases or data that refuted emerging understandings related to a theme.

My experience of use of qualitative data management software is that while these packages are helpful for grouping and clustering different sections of coded data, I have found it difficult to code directly onto data visible only on a small screen. That such a small segment of the text is visible at any one time can be disorientating and make the constant comparative method difficult to carry out systematically. For this reason I first coded both interview and observation data by hand, line-by-line (Glaser & Strauss 1967), annotating paper copies, and writing 'memos' (Glaser 1992) on the development of themes and sub-themes in the margins.

Returning to the raw data, I then typed up the observation notes for each participant, saved these at the end of the document containing the participant's interview data, and entered all this data into the data management package QSR*Nudist, saved under the participant's code name. Once all data was in QSR*Nudist, I coded it electronically, cross-referencing emerging themes with those recorded on paper copies in order to ensure thorough and reflective coding. These processes identified ten main themes, some with up to 11 sub-themes (see figures 5.1 and 5.2).

1. Things important to children in their lives
2. Pain
3. Children's social/emotional experiences of their illness and care
4. Processes of learning and understanding
5. Children's agency in relation to their care
6. Joint care
7. Children's clinical experiences
8. Issues in relation to ethnic identity
9. Methodological issues

Figure 3.1 Main themes in fieldwork

Sub-themes within 'Processes of learning and understanding'
4.1 Opaque learning processes
4.2 Learning by watching
4.3 Cyclical learning
4.4 Importance of visual appearance
4.5 Motivation to take on task arising from desire to reduce restrictions
4.6 Learning by practising over time
4.7 Social/experiential understanding of illness
4.8 Misunderstanding metaphors
4.9 Understanding based in physical sensation
4.10 Connecting physical with bio-medical

Figure 3.2: Example of sub-themes in fieldwork

I then printed out data by sub-theme, and re-read each to identify any further sub-themes, notes on which I annotated the data by hand. I then considered, within each sub-theme, the nature of children's responses by age, gender and ethnicity. This identified similarities and differences between different children's views and experiences, and explored relationships and patterns between these and children's age/gender/ethnicity.

In the course of these processes I began to see that data related to one of four key themes in the existing research literature (discussed in Chapter 2):

- children's agency (or not) in home and other settings
- experiencing long-term illness across physical, emotional and social spheres as interruption, restriction and difference
- children's experiences and learning about their bodies and illness
- the experiences of children as members of an ethnic minority group.

I was able to map data directly onto one of each of these four themes, as follows:

Theme in existing research literature	Related themes from data as set out in Figure 3.1
Children's agency within, and outside, the home	Children's agency in relation to their care Joint care (at home) Children's clinical experiences
Experiencing long-term illness across physical, emotional and social spheres as interruption, restriction and difference	Pain Children's social/emotional experiences of care
Children's learning about their bodies and illness	Processes of learning and understanding
The impact of poverty on minority ethnic health inequalities	Issues in relation to ethnic identity Physical environment at home (Health care interpreting)

Figure 3.3: Themes from existing literature and related study data

In light of this I structured my analysis around these four themes. They directly informed the four main headings which formed the framework for my written analysis of fieldwork data.

In the final chapter I reflect further on these approaches to fieldwork and my learning from my experiences of using them. In the next chapter I set out methods for collecting and analysing pre-existing data on children's experiences of illness and care.

Chapter 4: Methods for qualitative review

4.1 Introduction

In this chapter I describe my use of methods from systematic review to gather qualitative data from existing studies and my approach to analysis, or synthesis, of this data. As I explained at the opening of the previous chapter, I want to be clear that I searched for and read studies for the qualitative review prior to fieldwork data collection and analysis, but synthesised review data afterwards, as follows:

1. Searched for and read studies in qualitative review
2. Collected fieldwork data
3. Analysed fieldwork data
4. Synthesised findings from qualitative review and write up of fieldwork analysis

I will reflect further on these choices in the Conclusions chapter. It is also worth noting at this point that I worked as a co-researcher on one of the studies subsequently included in the review (Sutcliffe et al. 2004), and this undoubtedly impacted on my own findings, both in the fieldwork and the review. I will discuss this also in the Conclusions chapter.

4.2 Review question and rationale

My review question was 'What have children with type 1 diabetes or asthma told us about their experiences of their long-term illness and its care?'; and from this, to identify key aspects of patient-centred care for school-age children and levers and barriers to its achievement. I explain in the following section why I decided to include data on the experiences of children with asthma as well as type 1 diabetes.

It is ten years since David Sackett's editorial in the British Medical Journal identified qualitative approaches as the best methods for gathering data on patients' values and experiences (Sackett & Wennberg 1997), and this has been subsequently endorsed by Government (Department of Health 1999) and reiterated by health care researchers (Petticrew & Roberts 2003; Greenhalgh 2002; Mays & Pope 2000). Although this is not the first review of qualitative research into people's experiences of long-term illness (Barroso & Powell-Cope 2000; Thorne & Paterson 1998) it is perhaps unusual to carry out a review of qualitative work, using systematic methods, as one arm of data collection alongside a second primary data collection arm. I decided to do this so that findings from good, relevant previous studies would have maximum impact on overall findings from this work by being included in the systematic analysis of data - rather than just forming a general context or 'background' for the work as is more usual in conventional literature reviews. A second reason for adopting this approach was that the sample size would be increased, providing opportunities for exploring where findings were more likely to be generalisable across the experiences of children from a range of different backgrounds, and also where there are differences between the experiences of children from different geographical, ethnic and economic backgrounds. A third reason was, as commentators have pointed out, time is one of the few resources over which children have much control (Roberts 2000): a control that is important to children (Christensen 2002), and which some commentators have suggested is diminishing (Ennew 1994). We eat into children's time every time we ask them to take part in a research study. As such there is a moral and political imperative to ensure that we listen carefully to what children tell us (Roberts 2000), and not embark on further work until we are sure that we have learnt the lessons from what they have already told us.

4.3 Development of inclusion criteria

The experiences of children with asthma as well as those with diabetes were included so that I could begin to make a judgement on the extent to which children's experiences of type 1 diabetes might be generalisable to the experiences of those with other long-term illnesses; and, from this, the extent to which type 1 diabetes 'works' as a valid case study for other illnesses. I chose asthma since, like diabetes, most management activity takes place in non-clinical settings as part of children's everyday lives. A second reason was that preliminary searches seemed to indicate a greater volume of relevant work in this area, in particular with minority ethnic populations, compared with other paediatric long-term illnesses.

4.3.1 Age range

Previous work has suggested little is known about the perspectives of younger children on their diabetes care (Grey 2000; Greene 1999; Brandt 1998) and that the origins of deteriorating control through adolescence may lie in childhood (Dabadghao et al. 2001). In order to reduce the gap in our understandings of the experiences of younger children, I included only those studies where participants were aged 10 years (mean, or if not known, median) or younger.

4.3.2 Focus on children's experiences

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; Ory & Kronenfeld 1980). 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 of the child in the family context (Mayall 1996). For these reasons I decided to extract only findings on the perspectives of the ill child, rather than those of others in the family. I discuss this further in the Conclusions chapter. In early attempts at the review, I included all studies where children were interviewed, even those which focused overwhelmingly on the views of parents (Buford 2001; Ambrose 1997; Horner 1992). However, extracting children's perspectives from this latter group frequently proved unworkable in practice, since authors routinely report findings without identifying their source – for example: 'Teresa Garcia, however, has needed more family assistance with managing her juvenile diabetes' (Ambrose 1997, p6), rather than 'Mateo Martinez stated that he had been responsible for managing his juvenile diabetes from day one of his diagnosis' (Ambrose 1997, p 7). In order to ensure this review reflected children's perspectives, (rather than those of their parents or siblings) I decided to include only those studies where there was a clear and significant focus on the experiences of the child with long-term illness rather than those of the whole family: or as Jens Qvortrup has described it, studies where children were granted 'conceptual autonomy' (Qvortrup 1994).

4.3.3 Study types

Qualitative methods are particularly useful for exploring social process and the meanings that people bring to their everyday experiences (Mays & Pope 2000). Face-to-face, open-ended, qualitative methods which give children some control over the process of research are particularly useful for good data collection (Christensen & James 2001; O'Kane 2000). In order to ensure that findings from the review reflected the perspectives and priorities of young children as much as possible, I included only studies that:

- included amongst tools for data collection an instrument with open-ended questions delivered face-to-face with participants in order to capture qualitative data – for example, a semi-structured interview or discussion group. Structured instruments were not eligible. (Findings from relevant studies using structured instruments are included in the opening chapter on the current state of knowledge about managing paediatric type 1 diabetes.)

- analysed and reported data qualitatively. (Some studies collect data using qualitative approaches but then use a quantitative paradigm to analyse and report findings, which has a detrimental effect on validity (Petersen et al. 2004).)

Preliminary searches identified a number of journalistic reports of children's experiences of their diabetes or asthma, (for example Sutcliffe and colleagues 2003), which - being journalistic pieces - did not, understandably, include a focus on methodology. Since this precluded making any assessment of study quality and rigour, I decided that, although findings may have usefully contributed to this study, they could not be included.

4.3.4 Geography

I decided to include those studies carried out in areas with cultures likely to be either indirectly (through family ties) or directly familiar to potential participants in this study. I asked clinicians which countries are represented in the population of children attending their clinics in East London. Studies carried out in these, and areas with similar cultures were eligible for inclusion - specifically: Europe, including Turkey and Russia, Africa, North America, Australia, New Zealand, Caribbean, India, Pakistan and Bangladesh.

4.3.5 Dates

I searched for studies from 1980 onwards. This date limit was selected in order to seek literature on children's experiences within one generation (defined for the purpose of this work as 25 years) (Lucas et al. 2007).

4.4 Searching for and retrieving the studies

My approach to searching and retrieving studies was based on a rationale devised to underpin reviews of qualitative data: that searches should identify major 'schools of thought'; search across a broad range of disciplines; and include techniques to identify unindexed and unpublished work (Booth 2001). To this end I carried out a range of scoping searches which identified two broad categories of work in this field:

- studies carried out by clinical researchers which tended to focus on children's knowledge and understanding of bio-medical models
- studies carried out by social scientists which tended to focus on children's direct experiences of their illness.

In order to ensure identification of both these types of study, I searched a range of both health and social care databases for published papers: in

February and March 2005, Medline, PsycINFO, CINAHL (1982-) and, in July 2006, Applied Social Science Index and Abstracts, Sociological Abstracts, International Bibliography of the Social Sciences (1981-). I decided to use a qualitative filter (Hawaii Medical Library website 2004) to identify relevant studies, since these have been found to be an efficient use of researcher time (Kleijnen et al. 2006), alongside free text searches round the terms 'asthma$', 'diabet$, and child or related synonyms (see search example in Appendix 6).

As part of my search for unpublished studies and work in practitioner-focussed journals, in February 2005, I used the terms described above to search the electronic databases ChildData, and Dissertation Abstracts (DA). I was concerned at the low number of hits for DA (n=3) and so reran this search without the qualitative filter in July 2006. During scoping searches in ChildData I had also encountered problems with the qualitative filter, so did not use it for this database either.

I screened titles and retrieved those papers that matched the following criteria for inclusion. Where it was unclear whether or not studies were relevant, I checked the abstract. To recap, inclusion criteria were:

- Participants: children with asthma or type 1 diabetes with a mean (or if this is not given, median) age of 10 years or younger at commencement of the research

- Study focus: a significant focus in study findings on children's views of their long-term illness and care

- Methodology: inclusion of an open-ended instrument used flexibly to collect qualitative data on children's views of their long-term illness and/or care, and qualitative approach to analysis and reporting; demonstration of some attention to methodology

- Settings: carried out in Europe, North America, Australia, New Zealand, Africa, Caribbean, India, Bangladesh or Pakistan

- Date: published in 1980 onwards.

Via electronic searches I identified 1719 papers relating to children with diabetes or asthma. I screened the abstracts of these for papers that may have fallen within the review criteria. Of these, I then screened 67 papers in full and found 11 fitted the criteria – see table 4.1 below. I was already aware of one relevant unindexed and unpublished report from my earlier research in this area (Sutcliffe et al. 2004). However in order to locate other 'grey' literature (Booth 2001), I contacted a selection of field experts, including members of relevant advisory committees at the National Institute for Clinical Excellence who had been involved in the development of guidelines on paediatric type 1 diabetes (see Appendix 7). I also contacted first or corresponding authors of included studies (with the exceptions of Zahorik (Zahorik 1990) and Walsh (Walsh 1983) who could not be traced) to ask for details of any further relevant work. No additional relevant papers were located by this means. I also retrieved and reviewed for potential inclusion papers described in the literature reviews of included studies as focusing on children's views of their asthma or type 1 diabetes. This identified one additional study (Dell Clark 2003). I summarise these processes in table 4.1 over.

Source	Relevant studies (bracketed ones subsequently excluded)
Database: Medline (17 hits)	Rudestam et al. 2005 Boyle et al. 2004 Pradel et al. 2001 Ireland 1997
Databases: PsycInfo, CINAHL (127 hits)	Nabors et al. 2003 Meng & McConnell 2002 Miller 1999, (2003) Spezia 1991, (1996)
Databases: Sociological Abstracts; Applied Social Science Index and Abstracts (64 hits)	Rudestam et al. 2005 – duplicate since also identified in Medline search
Database: International Bibliography of the Social Sciences (1981-) (8 hits)	-
Database: Dissertation Abstracts (1000 hits)	Koinis Mitchell 2003 (Pradel 1999) Zahorik 1991 Walsh 1983
Database: ChildData (503 hits)	-
Contact with selection of field experts	-
My own earlier work	Sutcliffe et al. 2004
Contact with corresponding author of included studies	-
Handsearching bibliographies of included studies	Dell Clark 2003

Table 4.1 Sources of papers for the review

Three papers were subsequently excluded:

- Miller, 2003 (Miller 2003) because it was a methods-focussed report of the same study described in the included paper Miller 1999 (Miller 1999)
- Spezia 1996 (Spezia Faulkner 1996) because the included PhD thesis (Spezia 1991) that underpins this paper provided more information on children's views
- The Phd thesis (Pradel 1999) was also excluded as the included paper by Pradel (Pradel et al. 2001) described the same study, but with a focus purely on the sub-sample of children who took part in qualitative work.

4.5 Data extraction and management

Data on children's views of their long-term illness and its care were electronically scanned and entered into the qualitative data management package, QSR Nud.ist. Where data was collected from children over 10 years as well as under, these were also included since it was often not possible to separate these out from other findings. However, in line with commentators' warnings about the dangers of children's views being subsumed within those of the family (Mayall 1996), I did not extract data from parents, other adults or siblings of any age. I discuss this further in the Conclusions chapter.

4.6 Methodological quality

Five diabetes studies, seven asthma studies and one study that included both asthmatic and diabetic children fell within the inclusion criteria. I assessed the studies 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). While the structure and basic criteria of the original tool were retained, I amended indicators for assessing the extent to which individual criteria are met in order 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). Broad criteria and assessment indicators are set out in Appendix 8.

4.6.1 Quality of reporting

The first five criteria sought to establish studies' quality of reporting. The aims and objectives of all studies were clear. All authors provided adequate descriptions of why studies were carried out. The main problem with quality of reporting related to insufficient description of the sample. In five cases details of the class and/or ethnicity of participants were not provided (Nabors et al. 2003; Meng & McConnell 2002; Miller 1999; Ireland 1997; Zahorik 1990) and in three instances information on the sampling frame and/or the processes whereby participants were selected remained unclear (Dell Clark 2003; Meng & McConnell 2002; Miller 1999). Accounts of data collection and analyses were adequate, with the exception of three studies where details of qualitative analyses were absent (Dell Clark 2003; Koinis Mitchell 2003; Zahorik 1990).

4.6.2 Reliability and validity of data collection methods

The next four criteria sought to gauge the reliability and validity of data collection methods and methods of analysis. For the most part, authors demonstrated the reliability of their methods of data collection via explication of theoretical concepts underpinning the work, or (less frequently) reflection on contextual factors, such as the possible impact of data collection methods, persons carrying out the research or changes in the context in which the study took place. The exceptions to this were Meng (Meng & McConnell 2002), Boyle (Boyle et al. 2004), Nabors (Nabors et al. 2003) and Walsh (Walsh 1983). Apart from Zahorik (Zahorik 1990), at least some attempt to demonstrate the validity of data collection methods was made in almost all cases, for example by describing efforts to ensure accurate recording of data (taping interviews, double-checking interview transcriptions) or attempts to help children feel comfortable enough to express themselves freely - though the extent to which some of these were mitigated by other aspects of research design (Koinis Mitchell 2003) is discussed towards the end of this section. The validity of data collection in Nabor's study (Nabors et al. 2003) was compromised by a lack of clarity around whether group data was tape-recorded or not. Only one author provided sufficient description of the study setting to inform readers of the potential transferability of study findings to other contexts (Sutcliffe et al. 2004). The validity of data collection on children's views and experiences in the study by Koinis Mitchell (Koinis Mitchell 2003), may have been compromised by virtue of the fact that the interview was held in the context of a two hour session in which children were asked to complete eight other written questionnaires.

4.6.3 Reliability and validity of methods for data analysis

Nearly half of authors made some attempt at demonstrating the reliability of methods for analysis, for example by description of the use of data management tools to facilitate within and across case analysis (Boyle et al. 2004; Spezia 1991) routine identification of negative cases in data analysis, or use of independent raters to code data (Boyle et al. 2004; Ireland 1997; Meng & McConnell 2002; Nabors et al. 2003; Spezia 1991; Sutcliffe et al.

2004) but this aspect of methodology was weak for the purposes of this review across the remaining studies (Dell Clark 2003; Koinis Mitchell 2003; Miller 1999; Pradel et al. 2001; Rudestam et al. 2005; Walsh 1983; Zahorik 1990).

Some attempt to demonstrate the validity of approaches to data analysis was made by most authors, for example use of respondent validation (Ireland 1997), triangulation of data from different sources (Boyle et al. 2004; Sutcliffe et al. 2004; Dell Clark 2003; Meng & McConnell 2002; Pradel et al. 2001) or 'thick' description of data using contributor's terms and/or vignettes appended with participants' details (Sutcliffe et al. 2004; Koinis Mitchell 2003; Rudestam et al. 2005; Spezia 1991; Walsh 1983). However, the failure to provide an adequately 'thick' description of data with sufficient use of contributors' terms compromised the validity of a number of studies for the purposes of this review (Boyle et al. 2004; Meng & McConnell 2002; Nabors et al. 2003; Ireland 1997; Zahorik 1990). The lively narrative of Dell Clark (Dell Clark 2003) made an accessible read, though, in the section on diabetes, the author did not routinely support assertions about children's experiences with individual items of first order data; and Pradel's analysis was weakened by the fact that several of the quotations from children did not seem to fall in line with the author's assertions about the data (Pradel et al. 2001).

4.6.4 Grounding in children's perspectives

The final criterion sought to gauge the extent to which findings are rooted in children's own perspectives: do authors' choice of data collection methods and data analysis methods facilitate this, and have they involved children in the design and conduct of the study? In relation to the first of these, Dell Clark's (Dell Clark 2003) approach in relation to data collection was strong:

> I made each interview into a session of play, into which talk was inserted as relevant and natural to the play. I brought along a supply of toys… I treated the children as equals during this play, listened to them attentively and treated their opinions with respect (Dell Clark 2003, p152-3).

Other authors described attempts at helping children express themselves to a greater or lesser extent. Examples of greater efforts included using child-centred data collection techniques such as drawing (Sutcliffe et al. 2004; Pradel et al. 2001; Miller 1999; Walsh 1983), imaginary 'scenarios' (Spezia 1991) or other approaches using play or visual props (Rudestam et al. 2005; Sutcliffe et al. 2004; Dell Clark 2003). Other aspects of data collection which may have been helpful in this respect included piloting instruments with children (Sutcliffe et al. 2004; Dell Clark 2003; Spezia 1991); delivering instruments flexibly in child-friendly language (Rudestam et al. 2005; Sutcliffe et al. 2004; Dell Clark 2003; Meng & McConnell 2002; Miller 1999; Ireland 1997); centring questions around subjects familiar to children (Miller 1999; Sutcliffe et al. 2004); collecting data in familiar or comfortable surroundings (Boyle et al. 2004; Dell Clark 2003; Pradel et al. 2001; Ireland 1997); and reassuring children that the interview was not a test and they had no need to be nervous (Pradel et al. 2001). Though Koinis Mitchell (Koinis Mitchell 2003) described using vignettes about children with asthma to help participants describe their understandings of 'doing well' with their illness, her description of arranging this alongside the ''administration' of eight other 'instruments' over a session of more than two hours did not seem a helpful approach to understanding the experiences of children who are more likely to respond with valid answers when a flexible approach is used (Christensen & James 2001; O'Kane 2000).

The extent to which data analysis facilitated findings based in children's perspectives was gauged by examining the extent to which authors described their findings as drawn from patterns occurring within the data, rather than themes they had chosen prior to data collection. This was an approach used across nine studies (Rudestam et al. 2005; Boyle et al. 2004; Sutcliffe et al. 2004; Nabors et al. 2003; Meng & McConnell 2002; Miller 1999; Ireland 1997; Spezia 1991; Walsh 1983). Dell Clark's failure to include any description of data analysis procedures made it difficult to judge the study on this criterion. This was particularly the case given that in the section of the book on diabetes, the author does not always cite the items of first order data on which her assertions about children's experiences are based (Dell Clark 2003).

No author actively involved children in planning the design or carrying out the study. However seven studies reported providing children with opportunities to give their views on the data collection process, flag up additional questions, or used sufficiently open research tools that children's concerns and priorities were able to determine the course and conduct of data collection (Rudestam et al. 2005; Sutcliffe et al. 2004; Dell Clark 2003; Miller 1999; Ireland 1997; Spezia 1991; Walsh 1983). Given that this is a review of children's perspectives on their illness and care, such approaches seem especially important. It is interesting that with the exception of Dell Clark (Dell Clark 2003), these studies were also those with the smallest number of other methodological weaknesses. It seems likely they were all undertaken by researchers with a particular understanding of qualitative methods, and the importance, within this, of increasing validity by providing opportunities for participants to influence on the course and conduct of the project.

4.6.5 Overall quality of studies

The main problems lay in studies' failure to demonstrate reliability and validity of data analysis, and in many cases, participants' inability to influence the main course and conduct of the research (see Table 4.2 below). Lack of information on sample characteristics was also a problem and significantly limits the degree to which it is possible to judge the transferability of findings from the synthesis to other settings.

	Sample description	Description of methods of data analysis	Reliability of data collection	Validity of data collection	Reliability of data analysis	Validity of data analysis	Children's influence on conduct of study
Sutcliffe							
Spezia							
Ireland	•						
Rudestam					•		
Miller	•				•		
Walsh			•		•		
Dell Clark	•	•			•		
Koinis Mitchell		•		•	•		•
Nabors	•		•	•			•
Pradel					•	•	•
Boyle			•			•	•
Meng	•		•			•	•
Zahorik	•	•		•	•	•	•

Table 4.2 Methodological weaknesses for the purposes of this study

Shaded columns indicate areas of particular methodological weakness for the purposes of this study.

Decisions about where to put the 'cut-off' point to divide 'stronger' and 'weaker' studies will always be, to some extent, arbitrary. It was decided that those studies that facilitated children's influence on the course and conduct of the research are particularly useful for the purposes of this review (Rudestam et al. 2005; Sutcliffe et al. 2004; Miller 1999; Ireland 1997; Spezia 1991; Walsh 1983) since it seeks to explore children's perspectives, 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 is not included within this group of 'stronger' work, because of the omission of such a key aspect of methodology: description of how data was analysed.

4.7 Synthesis of review data

Methods for synthesising qualitative data are still under development (Popay et al. 2006; Dixon-Woods et al. 2005a) and to that extent, work in this area remains, to some degree, exploratory. Approaches to synthesising qualitative data from existing studies have been classed as either broadly integrative, where concepts from respective studies are summarised or aggregated, their meaning remaining relatively unchanged; or interpretive, where concepts are reinterpreted to build new theory (Dixon-Woods et al. 2005a; Noblit & Hare 1988). Integrative approaches have been found to be useful for mapping the scope of existing literature in a given field, and interpretive approaches useful for producing new understandings of material (Lucas et al. 2007; Popay et al. 2006).

In this section I describe how, unwilling to lose learning from the original studies, I first undertook an aggregative thematic synthesis of data (Dixon-Woods et al. 2005b), and then, unsatisfied with the extent to which these findings provided answers to my review questions, carried out a narrative synthesis comprising more interpretative work (Popay et al. 2006). I reflect on these experiences and my learning from these for our understandings of qualitative data synthesis in the Conclusions chapter.

4.7.1 Familiarisation with data

As with the fieldwork data, analysis of data began via an on-going process of "familiarisation" (Ritchie & Spencer 1994): reading and re-reading papers and transcripts, and noting emerging themes.

4.7.2 Extraction and management of data

I electronically scanned data on children's views of their long-term illness and entered into it into the qualitative data management package, QSR Nud.ist (Lewando-Hundt et al. 1997). Where data were collected from children over 10 years as well as under, these were also included, since it was often not possible to separate these out from other findings. However, in line with commentators warnings about the dangers of children's views being subsumed within those of the family (Mayall 1996), I did not extract data from parents, other adults or siblings (of any age). I discuss in my Conclusions chapter the salience of these views and the reason why they are not a key focus of this particular study.

4.7.3 Methodological assessment

Methods for systematic review of quantitative data incorporate assessment of study quality so that methodologically inadequate work can be excluded or methodological weaknesses made explicit and some guarantee or understanding established about the rigour of findings from the review (Petticrew & Roberts 2006). As I described in the previous section, all studies (including my own fieldwork study, presented here) were assessed against a set of criteria developed from existing work in the area (Spencer et al. 2003; Thomas et al. 2003) and classed as methodologically 'weaker' or 'stronger' for the purposes of this work. However, because of the contested nature of the assessment of qualitative data (Spencer et al. 2003; Booth 2001) I was reluctant to exclude studies. When, in future chapters, I refer to studies as methodologically 'weaker' or 'stronger', I mean that they are more or less methodologically sound for the purposes of this study.

4.7.4 Method 1: an aggregative, thematic synthesis

As I have described, when I embarked on this synthesis, my initial impetus was to adopt as aggregative an approach as possible, so as not to lose learning from the original studies. Many aggregative approaches, such as content analysis or case survey, are associated with a significant loss of the depth and detail of qualitative data (Dixon-Woods et al. 2005b). However, the exception to this is thematic analysis, where findings from prominent themes across studies are described under relevant headings (Dixon-Woods et al. 2005b). Some commentators have described thematic analysis as primarily interpretative (Lucas et al. 2007), but others point out how this depends on the degree of abstraction from original study concepts used in the development of over-arching themes (Dixon-Woods et al. 2005a). Where over-arching themes are descriptive or summative rather than involving a high level of reinterpretation, the approach is essentially aggregative.

Aggregative thematic synthesis has been criticised on two counts: first, that the processes of developing themes are opaque (Dixon-Woods et al. 2005b) and therefore the reliability of the process questionable (Lucas et al. 2007; and secondly, that contradictions and differences between studies with different populations can be lost in the final synthesis (Lucas et al. 2007; Dixon-Woods et al. 2005b;). I hoped that I would be able to address both these points by drawing on methods used in narrative synthesis (Popay et al. 2006). Specifically I wanted to explore whether the use of tabulations would aid transparency of the thematic synthesis and help me identify differences and similarities across different populations – just as the use of tables in Framework Analysis supports comparison of findings across different cases in primary data analysis (Ritchie & Spencer 1994).

a) Text / tabulated study summaries

First, in order to gain an overview of studies, I produced both textual (see Appendix 9, for an example) and tabulated summaries (see Appendices 10 and 11) of studies (Popay et al. 2006; Arai et al. 2007).

b) Thematic analysis

Next, I used grounded theory's constant comparative method (Glaser 1992) (see details in 2.5.1) to carry out line-by-line analysis of study findings in order to identify both themes identified by authors and themes I judged to arise from the data presented (Dixon-Woods et al. 2005a). While my identification of themes arising in the data sometimes involved a degree of reinterpretation of some authors' data, this was not extensive enough to qualify as data 'translation', where data from one study is purposely reassessed in light of concepts from another (Popay et al. 2006). I marked up coding first on Word versions of the documents and then coded data electronically in QSR Nud.ist to produce reports of data grouped by theme.

c) Data tabulation by study and theme

The third stage involved preparing data for exploring relationships within and across studies (Popay et al. 2006). This I did by using the cut and paste function in Word to tabulate data by study and theme, grouping studies by illness and country in order to facilitate comparison of data within and across these groups – see Appendix 12 for an example of data tabulated by theme from studies of children with asthma in USA.

In order to identify the concepts which would structure the final overview, I examined these data tables to assess how concepts in one study related to concepts in other studies and to develop summarising concepts that could incorporate all. This is a similar process to: 'translation as an approach to exploring relationships' (Popay et al. 2006) where concepts from one study are compared with those of another in order to assess their 'fit', but involves an emphasis on summary rather than reinterpretation. I then wrote up the review, using these summarising concepts as a framework and referring to data tables for details of data from individual studies.

4.7.5 Method 2: a narrative synthesis

Having completed the aggregative, thematic analysis, I was dissatisfied with the extent that this provided data I could use to answer my research questions about the nature and levers/barriers to patient-centred care. What I had was simply a detailed summary of data from included studies (see Appendix 13) which would need reinterpretation to answer my research questions. To this end I carried out a second attempt at synthesis, this time more closely following recent guidance on Narrative Synthesis (NS) (Popay et al. 2006) produced as part of the ESRC methods programme.

In their guidance on the conduct of NS, Popay and colleagues describe this as a process of synthesis where words and text are used to tell the 'story' of the findings from the included studies (Popay et al. 2006), a process that, once the development of the review question, searching and data extraction is complete, comprises three stages:

- Developing a preliminary synthesis
- Exploring relationships in the data
- Assessing the robustness of the synthesis product

a) Developing a preliminary synthesis

Popay and colleagues recommend compiling text and tabulated study summaries, which I had already completed as part of the previous synthesis (see 4.7.4 a). Next, again following the NS guidance, I grouped and clustered studies' key characteristics, specifically by participant age, illness or ethnicity, location of study and first author discipline; I have set these out in the findings chapter (Section 6.1). Finally, following Popay's third recommendation for completing the preliminary synthesis (Popay et al. 2006) I carried out another thematic analysis, but this time with a much higher degree of reinterpretation of data than I had used previously. I searched for themes relating to what, in the view of authors or myself helped or hindered children manage their day-to-day illness. This time instead of tabulating detailed data for each theme (see Appendix 12 for an example) I summarised themes in one short phrase and tabulated these for each study (see Appendix 14). In the course of this, I noticed that what helped or hindered children in their day-to-day management seemed to relate a) to the child and his/her beliefs/competencies; or b) to illness; or c) the regimen; or d) to wider environmental influences. I marked these categories on my tabulations of themes from each study, grouping themes as text under key headings study (see Appendix 14).

b) Exploring relationships in the data

Building on Popay and colleagues' guidance (Popay et al. 2006) and using my tabulation of themes (Appendix 14) as a framework, I explored, and wrote up as a narrative (see Chapter 6), describing how findings across studies, under each theme, varied by:

- population (illness, ethnicity, age)
- the methodological quality of studies
- researchers' divergent attitudes to and understandings of children and childhood (investigator triangulation) (Begley 1996; Popay et al. 2006).

At the end of each section, on each theme, I summarised what evidence across studies suggests we can know about children's experiences, the quality of this evidence and the populations to which it might apply.

As I 'translated' those findings across studies which over-lapped or had direct implications one for the other (though the same conceptual labels may not have been used) (Noblit & Hare 1988), the synthesis began to emerge. Popay and colleagues (Popay et al. 2006) suggest the use of figures or diagrams to record and explore the relationships between themes, and this proved particularly useful in the development of the synthesis.

I discuss my assessment of the robustness of the synthesis in the final section of the review findings chapter (Chapter 6). The next chapter, Chapter 5, sets out my findings from fieldwork. It is this report that I synthesised alongside findings from the review studies, to reach the overall findings from the study, described in Chapter 6.

Chapter 5: Fieldwork findings

In this chapter I set out findings from my fieldwork – home visits, clinic observations, and group discussions - on children's experiences and practices in managing their type 1 diabetes, alongside carers and clinicians. In the first section, I summarise details of children who took part in the study. I open the second section with a statement about children's agency and competence in managing their illness and care and how this contrasts with my observations of children's passive role in clinical interactions. I then describe how children seemed to experience their illness and its regimen as disruption on physical, social and psychological levels, before turning to look at how different children respond to these challenges. This leads into a discussion of the processes of children's understanding and learning about their illness and how this is supported in partnership working with carers in domestic settings. I end by summarising the implications of findings for clinical practice.

Although I emphasise in this chapter the importance of children's physical and social experiences, rather than age, in their learning and understanding about their illness, I have included reminders of children's ages, in brackets after their names, in order to demonstrate the differences and similarities in children's experiences and understandings, across ages, and challenge assumptions about younger children's competencies.

5.1 Children in the study

Between the autumn of 2005 and spring of 2007 I carried out in-depth qualitative fieldwork work to explore the views of children on managing their type 1 diabetes care alongside carers and clinical staff, with a self-selecting sample of 17 children drawn from the population of approximately 140 3-10 year-old children receiving care for type 1 diabetes at two paediatric diabetes clinics in East London. The first of these, in Newham, was held in a smart, newly built community health centre; the second, in Tower Hamlets, in an older building within a large Victorian hospital.

Between 22 December 2005 and 1 May 2007 I met with 17 children with a diagnosis of type 1 diabetes, at their homes and at the paediatric diabetes outpatients clinic. I met most children twice at home, usually for about an hour each time, and observed at least one of their clinic appointments. George and Marjan did not want me to observe their clinic appointments, which left enough time to observe two of Shadow and Girls Aloud's appointments. Zak, Sither and Shadow's mothers requested my second meeting with their sons to discuss their diabetes and its care take place at the clinic, when they would be attending for an appointment. I made four visits to Keith's home as, though he said that he enjoyed my visits, he was only willing to engage on his diabetes for short amounts of time. I also carried out 45 hours of observation in clinic waiting rooms.

Child's name	Home visits	Meetings at clinic
Spiderman	2	1 observation of appointment
Asma	2	1 observation of appointment
Marjan	2	Requested observation data not included
Lil' Bratz	2	1 observation of appointment
Trunks	2	1 observation of appointment
Keith	4	1 observation of appointment
Shadow	1 (mother requested clinic as venue for 2nd discussion)	2 observations of appointments and 1 discussion of care
Zak	1 (mother requested clinic as venue for 2nd discussion)	1 observation of appointment and 1 discussion of care
Girls Aloud	2	2 observations of appointments
Sither	1 (mother requested clinic as venue for 2nd discussion)	1 observation of appointment and 1 discussion of care
Spyro	2	1 observation of appointment
Lisa	2	1 observation of appointment
George	2	Requested appointment not observed
Shannon	2	1 observation of appointment
Emma	2	1 observation of appointment
Little Miss Perfect	2	1 observation of appointment
Ruben	2	1 observation of appointment

Table 5.1 Home visits and meetings with children at the clinic

The children were aged between 4 and 11 years: 8 girls and 9 boys. All except Little Miss Perfect were insulin-dependent. Two, siblings – Lisa and Spyro – were using pumps, the remainder received their insulin via a regimen of daily injections. There was one other set of siblings: Little Miss

Perfect and Trunks. All the participants had been diagnosed for more than a year, with the exception of Asma, and Lil' Bratz who had been diagnosed six months and seven months prior to my first meeting with them, respectively. Seven children had been diagnosed at age 3 or younger. I set out more details of children's ages, ethnicity and age at diagnosis in the tables below.

	Median age in years at fieldwork visits	Ethnicity	Age in years at diagnosis
Spiderman	4	White, English	1
Marjan	5	Somali	3
Asma	5	Somali	5
Trunks	6	Somali	6 -18 months
Keith	6	White, English	5
Lil' Bratz	6	Eastern European, Lithuanian	5
Zak	7	Somali	2
Shadow	7	Bengali, British	5
Girls Aloud	7	African	3
Sither	8	Somali	5
Spyro	8	Arabic	1
George	9	White, English	3
Shannon	9	White, English	8
Lisa	9	Arabic	2
Emma	10	White, British	4
Little Miss Perfect	10	Somali	8
Ruben	11	African/Portuguese	7

Table 5.2 Age, ethnicity and age at diagnosis for children participating in the fieldwork

The ethnic data in tables 5.2 and 5.3 refers to carers' descriptions of children's ethnic backgrounds; yet, it is worth noting that over the course of the study, children sometimes directly, or indirectly, challenged the perspectives of their parents or carers. For example, Lisa and Spyro's father described them as 'Arabic'. Asked whether she knows any other children with diabetes, Lisa said she does not. Her mother prompted her about 'the son of our friend' who has diabetes, to which Lisa responded 'oh yes! He's an Arabic person'. In her lack of recollection of this boy, and subsequent identification of him as 'an Arabic person' Lisa seems to set him apart from herself and her regular circle of friends on the basis of his being 'Arabic'. Girls Aloud's mother explained how much she is looking forward to a visit to her home country, Tanzania – 'this is my country!', whereas she described how Girls Aloud is concerned about the visit because of her experiences of Western media portrayal of Africa: 'the people there, the problems'. Conversely, when Shadow's mother described their ethnicity as 'British', Shadow, who lives in an area with a large White, as well as Bangladeshi population, queried, 'I look like British?' This indicates the complexity of children's identities and how their experiences growing up in the UK may render their understandings of their ethnicity as different from those of their parents.

5.2 Children at home and at the clinic

5.2.1 Children as joint participants with adults in their domestic health care

Just as previous researchers working with school-age children in general populations and with those with long-term illness discovered, I found that in my meetings with children, in their homes, most presented themselves as - and demonstrated themselves to be - competent and active partners in their domestic health care (Mayall 1999; Christensen 1998; Mayall 1998; Mayall 1996; Mayall 1994a; Alderson 1993). Children from 5 years and upwards showed a good knowledge of the timetable for their regimen of insulin injections, blood glucose tests and snacks:

> Katherine: Do you have another injection in the evening, or is it just one injection in the day?
> Lil' Bratz (6): Two! One in the morning when I go to breakfast and one in the afternoon when I have my tea.
>
> Katherine: So does your mum do your [blood test]?
> Marjan (5): She does it in the morning and the afternoon… three times a day: one is night and one is morning and one is afternoon.
>
> Katherine: And when do you have biscuits?
> Girls Aloud (7): I have it at school at 2.30 – I eat my apple at 10.30.

Children from 5 years-old and upwards reported doing their own finger prick on a regular basis, and described recognising the symptoms of hypoglycaemia and knowing how to respond to these:

> Lil Bratz (6): When I come back [home from school], I can inject my finger by myself!
>
> Katherine: How do you know that you're low when you wake up?
> Shadow (7): Because it just wakes me, I just feel so tired. It makes me feel like shaky and hands shake... and my legs just go up like that [shows trembly legs].
>
> Girls Aloud (7): Sometimes I feel dizzy at home and at school... I have to get enough lucozade.

Children from 6 years-old demonstrated familiarity with bio-medical models of hyperglycaemia and hypoglycaemia via recognition of the significance of blood glucose meter readings:

> Trunks (6): 3.2 – that means it's low.

Children from 7 years-old recounted experiences of doing their own insulin injections and showed knowledge of the impact of exercise on blood glucose levels:

> Sither (8): I used to do my leg, it's easy in my leg... I stopped it now because I keeped on doing it in there [sic].
>
> Katherine: Why do you have the banana?
> Shadow (7): Because my sugar level drop again, because I'm running around and using my energy.
>
> Spyro (8): If you do too much sport, you go low.

Children from 9 years-old reported doing their own injections on a fairly regular basis, and one, the oldest, Ruben (11), described doing most of his evening injections:

> Ruben (11): All you need to do is shake the pen, take the pen - before I have my injection, I take it, and then put the needle on it. Then I put how much units I'm going to have, and then I take it. And then, when I'm done, I just take off the needle 'cos it's like this thing that you can take off, and I put it in the bin and then I'm done.

Most children - across ages - showed knowledge of the importance of avoiding unhealthy foods:

> Katherine: Can Teddy eat what he wants?
> Asma (5): No… not allowed sugars!
>
> Katherine: Does Teddy have to eat special things?
> Marjan (5): He's not allowed to eat sweets… cos it's sugar.
> Katherine: Why is sugar bad for Teddy?
> Marjan (5): Because his sugar is not go out if he eat lots of sugar things.

Children readily identified healthy food options appropriate to the diabetes diet:

> Katherine: What would you have for breakfast?
> Little Miss Perfect (10): something, not like butter and toast, 'cos butter has lots of fat in it. Maybe some cornflakes, healthy cornflakes or weetabix.
>
> Katherine: Can you tell me which foods are good for Teddy with his diabetes [showing toys]?
> Asma (5): I know! [selects a banana, an orange and a pear over other choices of, for example, crisps and hot dog]

And, chiming with Parsons' account of illness as a social undesirable state from which restitution is only available via a process of striving for wellness (Parsons 1951), children routinely presented themselves as morally competent decision-makers in terms in making the 'right' decisions about food choices:

> Sither (8): When people have their birthdays [they give me sweets].
> Katherine: What do you do then?
> Sither (8): I ask my teacher, I don't eat it there, I take it home.
>
> Katherine: Sometimes your friends have sweets at school? What do you do then?
> Girls Aloud (7): I don't take them.

Several children described internalising recommendations for a healthy diet to the point of disliking restricted foods:

> Mother: She does miss her sweets, don't you Shannon?
> Shannon (9): Katherine, I don't like normal sugar, and I'm not really allowed it: I don't like it.

> Katherine: Do you wish you could still have school dinners?
> Lil' Bratz (6): Yeeesss – but I don't want school dinners, because they have afters and I don't like afters – even they have chocolate cakes and kind of ice creams.

Yet, while presenting themselves as active participants in their care, children were also explicit about the importance of the role of adults they live with – and the role of clinicians. For example, as part of the feedback discussion group, some children re-arranged symbols signifying, respectively, themselves, their carers, their doctor, their teachers and their friends in a hierarchy to represent each party's contribution to their daily care. Once Emma (9) was clear that I was asking about care at home, rather than at the clinic, she rearranged her symbols, from having clinicians at the top, to putting herself and her parents in the primary place of responsibility:

> Emma (10): can I change mine?... I want [Emma reorganises symbols]
> Katherine: [reading off symbols] So you are at the top with your mum and dad and then number two is the doctor and number three is your friends and teachers.

Spiderman (4) and George placed their parents at the top and themselves in second place; and furthermore, George (9) was clear about the central role of the consultant: 'No, I think the doctor, and mum and dad should be first.' In their narratives about care in the home children also indicated the centrality of carers' roles; for example, though many children described doing their own finger prick for blood tests, most reported carers playing an important part in reminding them to do this. Likewise, children who described doing their own injections were clear that carers reminded them about these and checked that they had been done. Further, some children's accounts indicated that they sometimes still preferred to share tasks with parents even once they were fully able to do these themselves. For instance, several children who reported confidence in doing their own finger prick also reported sharing this task with their mother; and most children in the clinic appointments I observed let their parents do their finger prick before testing.

> Shannon (9): My mum does it. I do it sometimes when she's like cooking the dinner.
>
> George (9): She does it sometimes… I do it at school.

Even Ruben (11), who reported regularly doing his own injection, described how he still prefers his mother to do the morning injection, when he is sleepy. I discuss children and carers' partnership working further in Section 5.7 on children's learning and understanding of their illness.

Finally, it was also clear from children's narratives and my observations in family homes that children can not only have a powerful impact in contributing to care, but also, if they wish, in resisting parental attempts to impose on them the diabetes regimen. For example, during my first visit to his home, Spiderman's (4) demands for ice cream were fierce and relentless, to the point where his mother capitulated – incidentally, calling into question Spiderman's model of care, described above, that places his parents above himself in terms of impact on day-to-day care. Likewise, Keith's grandmother confided how it is only with Keith's co-operation that she can implement the guide menus provided by clinicians:

> Keith's grandmother: [showing me the guide menu for meals and snacks for a week] … sometimes he's like, that was really nice, can I have it say two days later, and I think, well if he's going to eat it and he doesn't want to eat anything else, so I'd rather him eat, so he has it again and that's how I go.

Thus children's agency seemed to render implementation of the diabetes regimen a truly collaborative venture between children and carers. This contrasted with the model of care I observed in clinics, as I describe below.

5.2.2 Children's passive role in clinic settings

Mayall has argued that, in the home, carers' personal relationship with children and their vested interests in passing on some responsibilities for care provide greater opportunity for children to demonstrate their competencies than in other settings (Mayall 2002; Mayall 1996; Mayall 1994a; Mayall 1994b). Certainly, in sharp contrast to the active, confident participation in daily care which most children described - and demonstrated - in domestic settings, in the clinic appointments I observed, most children seemed passive and to contribute little. Most children's greatest contribution in the clinic was their physical presence for blood/urine testing, and height and weight measures, and their acquiescence with the processes of achieving these:

> [Extract from fieldnotes] Asma (5) follows the nurse's instructions to remove her shoes for weighing and then to come over to the height machine, and finally mum's instructions to wash her hands before the finger prick. After doing the finger prick she sits and watches the blood pressure sleeve inflating around her arm while mum asks the nurse about the building works in the hospital. Asma silently does what the adults ask. The main interaction is between adults.

> [Extract from fieldnotes] Dad does the finger prick and tells Spyro (8) the nurse will do his height and weight and to take his shoes off… the nurse gently pulls Spyro (8) under the height chart and holds her hands either side of his face [to hold him in place for measurement].

Clinicians' main interaction with children comprised friendly greetings and sometimes questions – often pertinent - about general, non-illness related aspects of their lives:

> Girls Aloud (7) and mum arrive. The diabetes specialist nurse (DSN) turns to Girls Aloud and says 'When are you going on holiday?' '12 July' says Girls Aloud. DSN asks Girls Aloud where she's going.

> Emma (10): There's [consultant's name] and [DSN's name].
> Katherine: What kind of things do they ask about?
> Emma (10): … about holidays, and what I am going to do, and, like, what I have been doing today.

Discussions of children's diabetes and care were mainly carried out in the third person, between clinicians and carers, as one carer put it 'as if [the children] are not there':

> Katherine: And what happens next?
> Sither (8): We meet [DSN] and she talks about my diabetic to my mum.
>
> Lisa (9): It's a bit rude to interrupt, so I don't like talking that much. Mostly we just sit and listen.
>
> [Extract from fieldnotes] Mum looks at Zak's (7) blood levels book. Zak sits on her lap and takes the book. Consultant asks mum about the insulin doses. He also asks mum how Zak feels when he's having a hypo. Zak stretches and looks at his mum.
>
> [Extract from fieldnotes] Mum describes how she's increased the evening insulin. Shadow (7) sits and listens. Mum reports how she does his blood test at school if she's working there that day... overwhelmingly discussions have Shadow in the third person... Mum reports Shadow has a tummy ache when high.
>
> [Extract from fieldnotes] After brief hellos, the consultant asks mum and DSN if Sither (8) is due his annual blood test or did he have it last time. Sither sits in the chair saying nothing.

With the exception of two older children, Ruben (11) and Emma (9), it was rare that children participated in these discussions. Lisa (9), whose father has a professional interest in endocrinology, described how she felt it appropriate that 'our dad talks mostly' as 'he knows all the information'. However, I would like to suggest that this meant that when children were praised for their personal contributions to care or exhorted by staff to a more active involvement in care at home, clinicians' words were undermined by the model of child as passive conveyed by the rest of their actions and words:

> [Extract from fieldnotes] DSN directly addresses Asma to praise her 'You're an absolute star, you've been doing very well', while [in the background] mum and the consultant discuss Asma in the third person.
>
> [Extract from fieldnotes] The consultant calls Lil' Bratz (6)... [he] asks if they are well... Mum and the consultant bend over the blood glucose meter looking at the readings. Lil' Bratz sits back in her chair and yawns. They continue to discuss 'she', 'her' (third person)... Lil' Bratz taps her feet... [she] sits on her hands and swings her legs. 'She's doing well' says the consultant (third person).

> [Extract from fieldnotes] DSN tells mum repeatedly the reason Sither is doing so well is because she manages his diabetes so well; it is not until the end of the appointment that the consultant acknowledges Sither's contribution also, but using third person: 'it's a credit to you – and to him too'.

In the instances when children did participate in discussion of their illness, it tended to be the diabetes specialist nurse (DSN) rather than the consultant who initiated this. Children at both clinics referred to their DSN by her first name, whereas the consultant was known to all, more formally, by his title and surname. Most children seemed to see the DSN as their main staff link at the clinic, and particularly valued her contribution to their care:

> Katherine: What about [DSN], do you know who [DSN name] is?
> Keith (6): Yes, she's my nurse!
> Katherine: What's she like?
> Keith (6): I like her!
>
> Ruben (11): And when it's low, sometimes… I have bananas.
> Katherine: … Banana makes it go up does it?
> Ruben (11): That's what my diabetic nurse said.

Children did not seem to view clinical interaction as something to which they could comfortably contribute:

> [Extract from fieldnotes] Girls Aloud (7) sits back in her chair and kicks her heels… when the DSN asks [her] how she is, she doesn't say anything, just looks down.
>
> Katherine: Would you like [DSN] to talk to you or do you prefer her to talk to your mum?
> Girls Aloud (7): To talk to mum.
>
> Katherine: Is there anything that you'd like to be different when you go and see [DSN]?
> George (9): How do you mean?
> Katherine: I don't know. Like if they explain things to you in a different way. Or if they talked more to you or less to you –
> George (9): Less to me!
> Katherine: Less to you?
> George (9): Yep!

Their questions were usually directed quietly to carers rather than clinicians:

> [Consultant describes how when they do the annual blood test they will also do an eye test and check Shadow's feet]. Shadow (7) leans over to mum and asks 'What is an eye test?'

And some described sometimes having difficulties concentrating during the appointment:

> Lisa (9): [giggling] I can't remember what we were saying 'cos Spyro kept kicking off my shoes so I couldn't concentrate at all.
>
> Katherine: [Looking at drawing] Who are all the people here?
> Little Miss Perfect (10): That's [older brother], that's my mum, that's Trunks, that's me. Me and Trunks sit on the chair and start giggling...
> Trunks (6): She makes me laugh.
> Little Miss Perfect (10): And he was giggling -
> Trunks (6): It was his fault!
> Older brother: No, I wasn't even laughing.
> Little Miss Perfect (10): He nearly laughed, he was bursting like this [takes big breath and holds it in].
> Katherine: It is cos the doctor's funny or is it 'cos you're not allowed to laugh?
> Little Miss Perfect (10): 'cos my mum and dad, they say not to laugh, my dad said not to laugh. And when you say not to laugh it starts it off.

Yet, while children seemed disengaged from interaction in clinic, they also showed a strong familiarity with clinic procedures:

> [Extract from fieldnotes] Asma (5) does her own finger prick, gives a sample to the blood nurse and puts some on the strip of her own blood glucose meter... She seems familiar with the physical layout of the clinic, for example knows the way to the loo to get a urine sample for the blood nurse.
>
> [Extract from fieldnotes] Shadow (7) comes into the blood test room without saying anything. He takes off his coat and jumper and washes his hands without anyone asking him to. He seems to know what to do.
>
> [Extract from fieldnotes] Mum asks for a new [blood glucose meter]. The consultant goes out. Emma (10) says she knows where they are, which cupboard.

Older children demonstrated a good understanding of parent-clinician discussions of blood glucose levels and the implications of these for their insulin doses:

> Katherine: Who decides how much insulin you have – your mum or the doctor?
> Trunks (6): Doctor!
> Little Miss Perfect (10): They change it. They look at his book and see how his sugar level goes and then they change it.

And although children sometimes seemed bored and detached during appointments (see notes of children's behaviour in extracts from fieldnotes above on discussion in clinic being mainly between carers/clinicians), children across ages also sometimes demonstrated an interest in proceedings or intervened with a suggestion, which hinted at a potential for further engagement at odds with their stated desires to 'just sit and listen':

> [Extract from fieldnotes] Mum asks DSN to write down how much sugar per litre of milk Shadow (7) can have in a milkshake. Shadow suggests they write it down in his blood level book. No one responds.
>
> [Extract from fieldnotes] The consultant asks mum which pen [injecting device] Zak (7) has, and asks to see it and what make it is. 'Accu-check" says Zak. "It's not Novo-pen-flex" says the consultant, ignoring him. Mum says it is. Zak gets up, stands next to mum and says quietly 'I can't remember the pen's name'.
>
> [Extract from fieldnotes] As DSN is praising mum for looking after Sither (8), Sither himself interjects that his doing so well is also down to all the exercise he does – 'football and karate'.

I will argue later that this interest on children's part indicates potential for their greater involvement in clinical interaction, (see Section 5.7 on children's learning about their illness and care).

In the next three sections, I want to turn to consider children's experiences of their illness and regimen. Building on frameworks from Bury's work with adults with long-term illness (Bury 1991) and Kyngäs' work with teenagers with diabetes in Finland (Kyngäs & Barlow 1995), I argue that children's experiences of diabetes and its regimen are of challenges across physical, psychosocial and emotional spheres. Both illness and regimen produce physical disruption, though of different types. Psychosocial disruption seems to occur both directly out of the illness and out of the regimen and to be exacerbated by children's low social status in school settings (Mayall 1996). Emotional disruption seems to arise directly out of the illness itself; and also out of enforcement of the regimen and/or an understanding of the illness as a moral undertaking whereby illness is seen as a social undesirable state from which restitution is only available via a process of striving for wellness (Parsons 1951).

5.3 Children's experiences of living with diabetes - physical disruption

5.3.1 Impact of hypoglycaemia and hyperglycaemia

Echoing Strauss and colleagues' (1984) and Bury's (1982) respective accounts of an adult illness 'trajectory', the outstanding characteristic of children's physical experience of the illness itself seemed its temporal nature, varying across time. Children described how they would feel fine and then suddenly faint, hungry and/or 'wobbly', 'dizzy', 'shaky'. Some children described times when symptoms escalated into much more overwhelming and extreme experiences of vomiting, extreme faintness or unconsciousness; and some had had recurrent experiences of this. Many children had been diagnosed in the context of a severe episode of hyperglycaemia, or diabetic ketoacidosis (DKA); and a few children described physical memories of times when they had had DKA:

> Emma (10): I remember when I was puking… I don't remember nothing else.
>
> Ruben (11): I just starting vomiting bile… I was still vomiting and I was feeling… I didn't have any energy.

Yet children's accounts resonated as much with their experiences of the regimen as with those of the illness itself. These seemed of a different order from experiences of the illness, perhaps because physical experiences of the illness itself tended to be more intermittent, while, as I describe below, those of the regimen were unremitting, sometimes overwhelmingly so.

5.3.2 Impact of relentless regimen of 'needles'

Children's narratives revealed their experiences of the regimen to be particularly overwhelming in relation to repeated puncturing of their skin by needles - for daily insulin injections or during treatment in hospital, or to obtain blood to test blood glucose levels daily, or, annually, at more length, to check the health of internal organs. It was striking that, in speech, some children tended to group finger pricks, for blood glucose tests, together with insulin injections:

> Katherine: Would you like to meet someone who had diabetes?
> Lil' Bratz (6): Yes
> Katherine: What would you talk to them about?
> Lil' Bratz (6): To not eat sugary things and [pause] to get your pricks five times a day.
>
> George (9): How many injections a day do you have?
> Emma (10): Including my [blood tests] it's five.
> George (9): five?
> Emma (10): Because I have to have three [blood tests] and two injections.

Likewise, some younger children used the term 'injection' to refer not only to insulin injections, but finger pricks as well:

> Katherine: Does your mum do your injection in the morning?
> Trunks (6): [nods] But at night-time I do it.
> Katherine: So you have two injections a day – or three?
> Trunks (6): when I'm going to eat I have to take my sugar in case.
>
> Katherine: Where does Teddy have the injection?
> Asma (5): Hand! Tummy!
>
> Katherine: Do you know what this is (showing blood glucose meter)?
> Girls Aloud (7): It's an injection.
>
> Marjan (4): Now Teddy needs to go to bed. First he has his injection. (Puts strip in blood glucose meter)

Yet, it was clear Marjan (5), Asma (5), Lil' Bratz (6), Trunks (6), Girls Aloud (7), and Emma (10) all understood the difference between an injection of insulin and a finger prick for blood glucose testing: Marjan (5), Lil' Bratz (6), Trunks (6) and Girls Aloud (7) each showed me how they do their finger prick and blood glucose test; in discussion Emma (10) distinguished between the 'needles… on my finger' and the two which are insulin injections; and when I asked Asma (5) if Teddy has anything in the morning apart from his insulin, she quickly responded 'Finger prick!' I would like to argue that Marjan, Asma, Lil' Bratz, Girls Aloud, Trunks and Emma did not display confusion about the nature of these respective tasks, but rather an understanding of the intervention that is strongly rooted in the physical sensation common to both: that of being 'pricked' or 'injected'. While the term 'injection' technically describes adding or introducing something, the four younger children appropriated it as a reference for their primary physical sensation of this: what they can feel. For them, an 'injection' has become any 'pricking' of the skin, whether to remove blood for glucose testing or to inject insulin.

This being the case then highlights a key attribute of children's physical experience of this part of their regimen: its unrelenting frequency. From 22 December 2005 when I made my first home visit, to Keith's house, to 1 May 2007 when I completed my last meeting, with Zak (7), a child on a daily regimen of three blood tests and two insulin injections would have experienced a total of 2470 finger pricks and injections; yet some children in this study carried out more than three blood tests a day, or needed to do a third insulin injection in the late afternoon, so would have experienced even more 'pricks' in that space of time. It is not surprising that, reflecting on life before she got her insulin pump, Lisa (9) reported that it is having injections 'everyday' that makes them difficult; that Asma (5) stressed how her injections are 'every, every, every day'; and that, asked how many times he has his injections Keith (6) responded 'Loads!... All the time!'

5.3.3 Impact of painful injections

With my focus here on children's grouping of finger pricks and injections into an interminable regimen of 'pricks', I do not mean to gloss over differences in children's experiences of injections, nor suggest that children did not also differentiate between the different degrees of pain or discomfort caused by finger pricks and insulin injections respectively. All those who spoke of the relative discomfort of finger pricks and insulin injections described the physical discomfort of finger pricks as 'not that much' (Shadow, 7); though George (10) added the proviso that – speaking from experience – you need to set the finger pricker at an appropriate depth setting otherwise 'it absolutely hurts... it stings'.

By contrast, Shadow (7), Zak (7), Emma (10) and Ruben (11) all identified insulin injections as the worst part of the regimen, though Ruben (10) also said injections 'don't really hurt' indicating that it is their impact on non-physical levels that is so disrupting, which I will broach in the next section. Trunks (6), Keith (6) and Marjan (5) reported the discomfort of injections in the stomach and Emma (10) of her morning insulin 'because it is 32... It's a long one... and in the evening it is only 12'. When I asked Asma (5) about how Teddy would feel about having injections she told me 'OK', though later her mother described how having to have her daily injections is very traumatic for Asma and she often 'screams'. Girls Aloud (7) was explicit about her anger about having to have daily injections, reporting, 'sometimes I get angry and I don't want to do it'. She annotated one of her pictures with the caption 'I like the park because no injections' and another with '... I hate injections'.

Further, children described the task of doing their own injections as considerably more unpleasant than that of doing their own finger pricks. Asked about their preferences for the age at which they would be ready to start doing their own injections, most children seem to want to put this task off for as long as possible, for example Asma (5), George (9), Zak (7) and Shadow (7) until their late teens. George (9) reported doing his own injection as 'horrible' and Emma (10) described how 'when I do it... I shake', which, in turn, causes bruising to her skin. The physical violence which repeated piercing of the skin can cause is also raised by Girls' Aloud's mother, who describes the bruising all over her daughter's body, caused by injections. In observations of children's appointments at the clinic, I regularly saw nurses checking children's injection sites for bruising and bumps.

Yet some children, across ages – Lil Bratz (6), and George (9) and Ruben (10) – stressed that the physical impact of their injections is not 'that bad' (George, 9) indicating that while for some children, this aspect of the regimen is extremely disrupting on a physical level, for others it is relatively unproblematic.

5.3.4 Relationship between experiences of needles during emergency hospital treatment and fears about routine tests in clinic

Several children – George (9), Asma (5) and Marjan (5) - raised their having to endure 'needles' when they were hospitalised, either at diagnosis or subsequently. All three indicated having a needle inserted in the back of their hand to be a central memory:

> Asma (5): [showing her drawing] This is me, this is mummy, this is the daddy and this is teddy, teddy, teddy there [pointing to teddy]... that's me and that's my cousin... this is the monster doctor.
> Katherine: What made the doctor a big scary monster... what did the doctor do to you?
> Asma (5): He put a needle in my skin... [shows the back of her hand]

Many children also expressed fear about the annual blood test carried out to check the health of children's internal organs. Unlike the instantaneous finger prick which draws blood for glucose testing, this involves inserting a needle in children's skin for some seconds while a cartridge of blood is drawn out for testing. Though there were a few exceptions, such as Little Miss Perfect (10) and her brother, Trunks (6), many children described this as disruptive on both physical and emotional levels:

> Girls Aloud (7): I hate having blood tests at the clinic.

> George (9): …it makes me feel it a bit sad… 'cos then I have to have an injection every year…
>
> Emma (10): Mum, I've just remembered I'm 10 now… I haven't [had the annual test], not when I'm 10… [DSN] said that to me last time that I had to have it, but I screamed… it hurts … that's why I never want to go [to the clinic].
>
> Lisa (9): We hate it.
> Spyro (8): I hate it.
> Lisa (9): … I don't like it. It really hurts because like it, they put it in for a very long time, it really hurts… they squeeze our arm as well and it really hurts when they squeeze it…
> Spyro (8): and you have to wear this tight thing, do you know what it's called? ...they sort of wrap it round, tight?
> Katherine: … If you knew a child who hadn't ever gone to have that done, is there anything that could happen that could make it better for them?
> Spyro (8): Well we usually have some cream so it wouldn't hurt.

Lisa (9) and Spyro (8), above, describe some of the aspects of this experience that make it physically unpleasant: that a tight tourniquet may have to be put around the arm and that the needle is inserted for what feels like 'a very long time.' Spyro (8) also referred to the anaesthetic cream which children are routinely offered and which he seems to indicate does dull the discomfort of the experience; though it seems not all children seem as reassured by this as Spyro (8):

> [Excerpt from field notes] George requested I didn't view his appointment with consultant because he was due to have his annual blood test, though I was in the clinic that day anyway… when [consultant] comes in [to the waiting room, George] asks him if he's having his 'injection' (sic) this time and [consultant] says yes, but he can have the magic cream. G looks horrified and protests that [DSN] said last time he wouldn't have [the blood test] this time.

George's (9) account, below, indicates why this might be so. He reports how the disruption of this process is as much about immediate physical impact as emotional distress at memories of a needle being inserted in the back of his hand during treatment for diabetic ketoacidosis:

> Katherine: [You said] you were worried it would be like when you had ketones in the hospital?
> George (9): Yeah
> Katherine: And what was the needle like then?
> George (9): Just - it was really small. My mum told me it wouldn't hurt like that because ... because it didn't have the tube in. Because normally I have to have a tube in my hand.
> Katherine: Right. This is when you had ketones?
> George (9): Yeah like… every time I have it.
> Katherine: And you said it was a big needle and you felt it sort of -
> George (9): Yeah, bends… Yeah, it was horrible, I didn't like it.
> Katherine: But the needle was different from that?
> George (9): Yeah… Mum just mentioned I have to have another injection… because they done the physical test on me and they got it wrong by mistake.
> Katherine: Right so you have to have another one on Tuesday – how do you feel about that one?
> George (9): Sort of ok.
> Katherine: Is that because you know that it's a smaller needle now, not the ketone one?
> George (9): Uh-huh.

This indicates it would be useful for clinicians to discuss with children fears arising from previous experiences and how these may or may not be relevant to routine care in the clinic.

5.3.5 Impact of loss and longing for restricted foods

Alongside the 'needles', the diabetes regimen requires that children on pre-set doses of insulin – as opposed to those using pumps whose doses are adjusted to food intake – must restrict their intake of sweets, puddings and particularly fatty foods. Much is made of the social and emotional implications of this, but I would like to suggest that, in this study, children's narratives made clear that, unsurprisingly, this is challenging on a physical level as well. Trunks (6) was sitting listening to his sister describe to me how their mother now regularly refuses them sweets on the basis of advice from the clinic dietician, when he spontaneously breathed a lengthy sigh of 'Chooooooocolate' and then lamented 'This is making me hungry!' Likewise, I was in the midst of a discussion with George (9) about his regimen of insulin injections, when he suddenly broke off to tell me about his visit to Pizza Hut that morning – 'They do like cheesy garlic breads… Like'em? …I love'em! I ate them today. Ooooooooh, nice. Creeeeaaaamy.

And all burnt and yummy'; and then later volunteered, 'You know, a fry up in the morning has seven types of food... mushrooms, tomatoes, they put hash browns in it now, egg, sausage, and bacon and some fried bread maybe'. Here, the two boys highlight the physical experiences of loss and longing brought about by this aspect of the regimen: like the 'needles' children must endure, an experience of relentless intrusion and frequency, potentially arising at every point in the day when the child with diabetes comes into contact with, and refuses, restricted foods.

5.4 Children's experiences of living with diabetes - psychosocial disruption

5.4.1 Social restriction, interruption and difference arising out of the onset of symptoms

Children's physical experiences of their illness had immediate social consequences in their lives in terms of restricting or interrupting their day-to-day activities, or setting them apart from others (Bury 1982). For example, Lisa (9) recounted how her brother, Spyro, 'really wanted to go to this special [football club] but it was like five hours in a day which is a bit of a problem for diabetes... cos you might go really, really low, 'cos it's lots and lots of training.' Although Sither (8) spontaneously asserted that during PE 'I don't feel my shake, I don't feel it', it is easy to understand why if he did, he might be reluctant to interrupt an activity he enjoys so much. Little Miss Perfect (10) described how she dislikes being the centre of attention when 'everyone starts going around you' when her sugar is low at school.

5.4.2 Social restriction as a result of the diabetes diet

Clearly, the diabetes diet also impacts at psychosocial levels. With the exception of Girls Aloud (7) who reported, with great sadness, that she only ever had sweets 'when my sugar's down', most children described having some of these foods in moderation. Yet this did not seem to mitigate their sense of restriction and loss:

> Shadow (7): I feel sad 'cos I can't have chips.

> Emma (10): I'm not allowed cake and custard, I have to have either cake or custard.... I only have like the little Kitkats.

> Katherine: And what would you tell Teddy is the worst thing about diabetes?
> Marjan (5): Not eat chocolate, just once!

Shannon's mother described how when she told Shannon she had a sweet tooth, Shannon responded that she wanted to 'pull it out' so that she didn't long for sweets so much. Both Shannon (9) and Marjan (5) spoke of food restrictions as the worst part of the diabetes regimen. This is unsurprising, not only because of the physical enjoyment associated with these foods – already described – but also their symbolic value as treats, gifts, tokens of celebration, prizes or rewards. Given the heightening effect of restriction on symbolic value and physical enjoyment, it is perhaps inevitable, though ironic, that these kinds of foods were still accorded this kind of status in children's families. On occasions when children had restricted foods, this was a 'treat', sometimes even offered for co-operation with the diabetes regimen – for example, as a reward for undergoing the annual blood test, Asma (5) was offered 'whatever you say, you can have it' for lunch, and Keith (6) a trip to McDonald's.

5.4.3 Sense of being different arising out of diabetes diet

However, it is not simply the sense of restriction, but that of difference from others that children reported to be difficult in relation to their diet. In a letter about her experiences of her regimen Emma (10) recounts how 'Sometimes I feel left out when I see all my friends eating sweets and chocolate'. A particularly acute aspect of the regimen, in setting children apart from peers, seemed having 'snacks' at school, since they are routinely consumed in the classroom in front of other children when no one else is eating. As George (9) describes this 'puts me off really'; and is a particularly uncomfortable experience for Shannon (9) who sometimes has to have her snack in assembly:

> Katherine: So you used to feel funny about having your [snack]?
> Shannon (9): I still do because sometimes when we are like in assembly I have to because we mostly do it about 1.30 and stuff and it goes on to about 3 or something.
> Shannon's mother: And you have to take it into the hall with you and do it there.
> Katherine: Ah, what's different about the hall?
> Shannon (9): Like every kid in the school is there.

5.4.4 Restriction, interruption and difference: social impact of the regimen of 'needles'

The diabetes diet is not, of course, the only part of the regimen which challenges children at a psychosocial level. Children's accounts made clear how the regimen of finger pricks and insulin tests are disrupting on a social as well as physical level, in terms of restriction and interruption to day-to-day activities, and causing children to stand out as different from peers (Bury 1982). As Emma (10) put it, the needles are as much a literal 'pain in the bum' as a metaphorical one. For example, Asma (5), Trunks (6), Spyro (8), Lisa (9) and Shannon (9) all described how they are not allowed to stay overnight at friends' houses:

> Spyro (8): The [bad] thing about diabetes is no sleepovers.
>
> Katherine: Why couldn't you stay?
> Asma (5): Mummy didn't let me.
> Katherine: Why was that? Do you know why? [pause]
> Asma's mother: What do you need to do in the morning?
> Asma (5): Insulin
> Asma's mother: And if mum's not there, who's going to do it for you?

Ruben (11) reported that he sometimes 'forgot' his insulin, because he was 'too busy doing other things'. He described the difference which this confers on him in relation to peers as particularly disrupting: 'I have to take injections and other people don't'.

5.4.5 Difference exacerbated in school settings

Mayall has described how the different relationship between adults and children in the home, compared with school settings, provide children with more opportunities to demonstrate their health care competence (Mayall 1994a; Mayall 1994b). Equally, in this study it sometimes seemed that while teachers and support workers at school were often helpful, for example in reminding children about snacks, arrangements for looking after children's diabetes at school sometimes seemed to cause more disruption to their day-to-day activities than in home settings. Sometimes this related to the division of labour amongst staff in the school, so that for example, Lisa (9) and Spyro (8) have to visit the school nurse at the health centre for their blood tests and insulin boluses from their pumps before, and after, lunch everyday. When reflecting on what they would be happy about if they no longer had diabetes, both Lisa (9) and Spyro (8) light on freedom from this trip, which as Lisa (9) puts it 'wastes my playtime', rather than freedom from blood tests and insulin altogether.

At other times disruption in school settings seemed to relate to what Christensen has identified as the adult need to 'legitimise' or act as arbiter over children's experiences of illness (Christensen 1998). For example, when George (9) recounted how at school his lucozade is kept in the school office, I asked him whether he decides when he needs it or whether the adult in the office decides, to which he replied: 'no they decide to have it, but they always tell me to have it.' It seems that although the adult at some level acknowledges that George's judgement is competent, the requirement for token adult 'legitimisation' remains, so that George (9) has to make a trip to the school office, rather than keeping his lucozade somewhere at hand in his classroom where he could access it with minimum disruption.

Sometimes the reasons behind disruptive practices were not always immediately clear; for example, both children in the sample who carried out blood tests at school had to keep their blood testing kit in places they could not access without adult help – Shadow (6) in the school office and Asma (5) in a high drawer in a disused disabled toilet near her classroom:

> Asma (5): 'the top drawer is like this, it's very high, I can't really reach it – I tell Mrs C, she is the first one that keeps an eye on me, and she normally gets the finger prick for me.'

Likewise, while Emma (10), Lisa (9), Zak (7) and Shannon (9) reported that at school they keep their snacks in a tin in their desk, or school bag or tray, where they can get to them easily - and Emma (10) described how her lucozade is stored in a cupboard so that 'if I feel really shaky I just walk to the cupboard' - George (9) and Lil Bratz (6) reported that their biscuits are kept by the teacher, and that they have to ask for them at snack time; and Shadow (7) described having to go down to the school office twice a day to get his snack, sometimes only to find it inaccessible:

> Shadow (7): ... and when I go to the office, for like when I have playtime I go and get my snacks and my sugar level done... I go to the office twice a day... and one day when I was eating, yeah, I came down there and I went to my class yeah and if they're not outside I just go back to my class... one day I went back to my class yeah and they were about to come down, so I was a bit early.

Zak (7) reported that while he kept his apple in his tray, his teacher kept his biscuits so that no one else would take them. It was not clear from children's narratives whether this was also the reasoning behind other teachers' restriction of children's access to their snacks or testing kits, but this highlights the tendency for adults to arbitrate children's health behaviour and how adult desires to protect children may limit children's power over their own lives (Alderson 1993).

5.4.6 Interruption caused by clinic attendance

Before moving on to consider further emotional challenges children experienced as a result of their illness and care, I want to briefly draw attention to two areas where there was a small, but significant amount of data indicating psychosocial disruption. The first of these relates to how attendance at the clinic sometimes interrupted children's participation in favoured activities, including – ironically, given the importance of exercise in the regimen – Wednesday afternoon sports:

> [Extract from fieldnotes] In the waiting room Sither (8) tells me he doesn't mind missing his football match for the appointment but in the appointment his mum tells clinicians that he's very upset about it.
>
> Spyro (8): I would definitely like to stay at school [instead of go to the clinic] because on Wednesday we do sport.
>
> Emma (10): Sometimes I feel like staying at school because we are doing art and then I have to go home [for clinic].

This may seem a small point, however, in the next section I address why it could be of considerable significance for children.

5.4.7 Interruption caused by problems with technology

Several children seemed to enjoy their competence in working the technologies associated with their care. For example, George (9) reported that 'it is fun to like make things work that are hard to figure out', and both Lisa (9) and Spyro (8) showed enthusiasm in describing the workings of their pumps:

> Lisa (9): First you press that to switch it on, and that's cancel, you cancel the whole thing, so you actually switch it off. So you press this to switch it on, you give like 1.5 let's say, and then you press 'ACT' and wait for it to beep 15 times – It beeps how many times you give it. And once it's finished you press ACT and then it's finished.

Indeed the only person I saw struggle to work out how to function the technology associated with care was a clinician having difficulty working a new blood glucose meter. However, several children described incidents in which failures of the technology on which they rely caused disruption on physical and psychosocial levels. Emma (10) described how a low battery in her blood glucose meter caused the meter to give a false reading of her blood sugar levels, causing both her, and her mother, considerable upset:

> Emma (10): ... last term in was my birthday I had a sleepover and on that day I went really shaky and [the blood glucose meter] said that I was ten ... so I just said to mum I feel really shaky so I had some Maltezers and then we tried doing it again and then I was fine... And she was going to cancel my sleepover!

> Emma's mother: I felt terrible because I didn't believe her, the machine's never been wrong since she's been diagnosed. And I just thought it was 'cos she could see all the cakes and ... I thought she might be trying it on 'cos she wants some of this now and I was like, no Emma, you're a bit high, your blood's ten, and then within about 20 minutes I looked at her and her eyes were, she was just crying non-stop and I thought something's not right and we done in it again, we changed the chip didn't we, and it showed something like two. And I cried 'cos I felt terrible that I hadn't believed her.

Likewise Lisa (9) described how if the insulin cartridge on her pump runs out 'we don't know what to do. So our mum has to come to school and if she's studying, because she has to be a doctor, then it's a bit of a problem. She has to come to school. And our dad works in X and it's far, it's like on the motorway. So there's a little problem when there's an alarm [signifying an empty cartridge]'.

While few children raised these issues, it may be that children with illness where care in organised more extensively around technology, or more sophisticated technology, problems with knowing how to work this or faults with the machines themselves may be a significant cause of disruption.

5.5 Children's experiences of living with diabetes - emotional disruption

I have already described how children's physical and social experiences of the regimen gave rise to challenges on an emotional level. In this section I want to discuss further emotional disruption that seemed to arise for children on three fronts: directly out of the illness itself, out of adult enforcement of the regimen, and/or out of children's understanding of the illness as a moral undertaking.

5.5.1 Impact of knowledge of morbidity and mortality

In their work with teenagers in Finland (Kyngäs & Barlow 1995) Kyngäs and Barlow found young people to experience significant psychological distress arising out of fears about long-term health complications relating to type 1 diabetes. Only a small number of children in this study raised the threat of morbidity and mortality arising from their illness. Zak (7) recounted how once when his blood was low 'nobody can wake me up'; George (9) also described the danger from 'hypos' that 'probably they wouldn't be able to wake you up'; Sither (8) volunteered that 'children should not eat sweets 'cos they could go blind'; and at a discussion group George (9) and Ruben (11) also discussed potential future threats to health:

> Ruben (11): The last time I went to see [DSN] in like one of her offices that she worked in, there was this poster about diabetes and it said if you don't take care of your diabetes properly it can lead blindness.
> George (9): And you lose a leg.
> Katherine: And did you talk to [DSN] about that?
> Ruben (11): No… 'cos you're too nervous.
> Katherine: Does it worry you in the future when you think about yourself growing up?
> Ruben (11): Yeah, 'cos sometimes when I think that if I miss my injections [or have] too many sweets and my sugar goes high, I've got to calm down.

Since I would not be in contact with children on an on-going basis to provide information and support around issues raised in the study which might worry them, and since I could not be sure whether or not they could find this support elsewhere, it seemed unethical to routinely raise issues with them that might frighten or worry them, but rather to follow children's lead if they broached these themselves. So I do not know for sure whether other children's reticence in this area was due to lack of knowledge about morbidity and mortality from type 1 diabetes or whether, like the children in Bluebond-Langner's study (Bluebond-Langner 1978) they wished to shield me, as an adult, from their understanding of this. However, the latter seems more likely as children did not seem to be routinely protected by adults from knowledge about threats – unlike in Bluebond-Langner's study (Bluebond-Langner 1978). For example, literature for adults on type 1 diabetes and potential long-term complications was readily available in one clinic and I observed children routinely reading leaflets as a way of passing the time in the waiting room or appointment. Further, I observed at least five children party to parental narratives of how, on diagnosis, they got to the hospital 'just in time' or how, since, 'she's nearly died'; and one mother described how adults had named the local support group for children with type 1 diabetes and their carers after a child who died during an episode of diabetic ketoacidosis. She recounted how, as a result, 'every time [George] hears the word ketones he thinks he's going to die'.

This suggests both, on the one hand, that younger children with diabetes, as well as teenagers (Kyngäs & Barlow 1995), may experience psychological disruption as a result of fears about the long-term consequences of their illness for their health; and also, on the other hand, that because of their understanding of adult disquiet around child morbidity and mortality, children are reluctant – or 'nervous' as Ruben (10) put it – to raise these issues, which perhaps exacerbates the sharing of inaccurate or misleading ideas.

5.5.2 Impact of adult enforcement of the regimen

Most children were reticent about the emotional distress caused by adult enforcement of the regimen. For example, I have already described how, when I asked Asma (5) about how Teddy would feel about having injections, she told me 'OK' though later her mother described how having to have her daily injections is very traumatic for Asma and she often 'screams'. However – again, as I have already recounted - Girls Aloud (7) was explicit about her anger about having to have daily injections, reporting, 'sometimes I get angry and I don't want to do it'. She annotated one of her pictures with the caption 'I like the park because no injections' and another with '... I hate injections'. Spiderman (4) was probably the most explicit in demonstrating distress about adult enforcement of dietary restrictions. As we sat waiting for his appointment with the consultant, his mother gave him a piece of doughnut:

> [Extract from field notes] Later he cries and throws [the doughnut] at his dad when mum says he can't have any more and continues crying and restless as we wait… [When we go into the consultant's office] Spiderman is still upset about not having the doughnut and sits on his mum's lap facing her, back to the room. He makes a loud wheezing noise [as he cries].

Likewise, the first time I visited Spiderman at his home, he and I were playing with a boy doll, who we had agreed to have diabetes, when I asked 'Can he have anything he likes for breakfast?' Immediately Spiderman stopped play with the doll and said 'I'm going away'. He returned shortly with some sweets that he had found elsewhere in the house:

> Spiderman's mother: No you can't have one of them!
> Spiderman (4): I want one!
> Spiderman's mother: You can't have any more of them. No! [she takes them from him with a small tussle].

This was one of the few occasions when I directly witnessed the emotional upset which enforcing the regimen causes children, and their carers. However, carers described other occasions on which children had to be held still to have injections or became upset because they could not have food they wanted.

5.5.3 Impact of the regimen as a moral undertaking

Before moving on to discuss the third front on which children seemed to experience emotional disruption, I want first to consider common understandings of the regimen as a moral undertaking. Returning once again to think about the Parsonian moral framing of the illness state (Parsons 1951), one might imagine that the exile of those with long-term illness to the abyss of social undesirability, while damaging to the social self, might at least free individuals from the moral imperative of constant strivings to a different illness/wellness status. Unfortunately, this appears to be far from the case, since, in children, carers and clinicians' narratives – and my own talk too - 'wellness' as the morally desirable state is replaced by either on-going and sanguine adherence to the diabetes regimen and/or achievement of optimum blood glucose levels: 'wellness in diabetes terms'. For example, when Zak (7) did his blood test and told me his level is 5.2, I asked him 'Is that good or bad' and he responded 'Good'. Here, it is me, the researcher, who is setting the moral agenda. However, as described in other accounts of diabetes management (Silverman 1987) clearly the origins of this lie in the clinical framework for optimum management of the illness, and clinicians' communications about this. That these - in the appointments I observed - seemed to be mainly framed very positively in terms of praise for carers when children are 'doing well', did not disguise this:

> Katherine: Why do you have to go and see [consultant] and [DSN]?...
> Lisa (9): What happens is our mum and dad tell us about our blood sugar and everything and whether we've been high or low and then the doctor has to figure out whether that's good or bad.
>
> Little Miss Perfect (10): [In the appointment they write down] how did we improve our sugar level....

Of course, the agenda is communicated much more routinely to children via their carers:

> Spiderman's mother: Shall we see what number's come up? 6.1 Well done! You've been good.

- and so, not surprisingly, appears in many children's narratives about their daily care, both in terms of the desirability of achieving optimum blood glucose levels:

> Lisa (9): ... and you mustn't have like too much sweets in your lunch box 'cos otherwise you go really high and that's really bad.
>
> Katherine: So you go down there and – what's it for, the blood test, what's it testing.
> George (9): Testing how much sugar I've got in my body.
> Katherine: What if comes out with the answer five.
> George (9): That is really good... If I had too much chocolate then that would go up.

> Ruben (11): Yeah. If you were like seven, would you have a different snack. If it was seven before I went to sleep I will have something with sugar because it will make it go high but that would good because at night it goes down then I'll be going down and I'll be normal, something like eight.

- and in terms of the desirability of adherence to the diabetes regimen, which in turn lends a status to certain foods and practices :

> Lil' Bratz (6): There are some kinds of chocolate, these kind of chocolates, they don't have sugar, they don't feel sweet.
> Katherine: When do you have those?
> Lil' Bratz (6): when I – when I be good and I eat my lunch and my dinner.
>
> Asma (5): [Holding up plastic models] This is an egg! Euhhhh!
> Katherine: Can you make the sound whether you like them or not…
> Asma (5): Nice! This is broccoli – yummy!
> Asma's mother: Are you sure about that...
>
> Katherine: Is this a cookie?
> Asma (5): No! It's a chocolate cookie!
> Katherine: So is it nice or yuk?
> Asma (5): yuk! Yuk! …

As I have already described in the opening section – and in line with Parsons' account of illness as socially undesirable, redeemable only via striving to return to wellness (Parsons 1951) - children frequently described themselves making the 'right' choice in terms of their diabetes – for example:

> Katherine: When do you have sweeties?
> Little Miss Perfect (10): Ummmm, our friends, our neighbours sometimes, they give us some of theirs [mum says] ok but you shouldn't eat it all - because sometimes I don't finish, I hide it… They give one to me, and if they give me an ice lolly I always put it in the freezer. I tell my mum…

However, what I want to argue here is that, understandably, the struggle to do this has an emotional toll, which Lisa (9) hints at below in her description of her wavering over food choices:

> Katherine: What do you do [about choosing food] when you go to parties – like you're going to a party this afternoon.
> Lisa (9): … I'm not sure, should I have this, should I have that? All the nice things over there, and all the good things for you.

This is also implied in two of Shadow's (7) remarks below, both of which seem to show him strung between his enjoyment of food he likes and his understanding of its negative moral status within the diabetes regimen:

> Shadow (7): The good thing is that sometimes I can have chocolate - but the chocolate is fat.

> Shadow's mother: Do you feel sad that you got diabetes sometimes or–
> Shadow (7): I feel sad and happy.
> Katherine: What bit makes you feel sad?
> Shadow (7): When I do my insulin and my blood test. And the happy bit is when… I can have good food and bad food.

When I observed Shadow's appointment with the nutritionist, she reminded him how eating sweet and fatty foods is not good for anyone and that following the diabetes diet is the same as following any healthy diet. While this is true, and I will discuss it further in the next section, children's narratives revealed the regularity with which they are exposed to restricted foods: daily school puddings, friends and siblings enjoying sweets or fast food as part of their daily diet and/or as rewards and celebrations. Bearing this in mind it becomes clear how constantly children must strive to make the 'right' choice, an on-going struggle as unremitting as the endless regimen of needles.

Finally, children were largely stoical about the challenges in their experiences of their illness and regimen. I would like to argue that this relates to a further moral imperative apparent in the narratives of some: that not only should they adhere to the regimen, but that they should do so uncomplainingly. I have already discussed how Asma (5) glossed over her distress at her daily injections. She is also quick to volunteer, in talking about her diagnosis – 'I didn't cry'. Likewise, Emma (10) plays down her feelings about the diabetes diet, but the tone of her answer belies her forbearance:

> Katherine: What kinds of things do you have to eat for the diabetes?
> Emma (10): Fruit, veg.
> Katherine: Do you feel sad about having quite healthy foods or are you alright about it?
> Emma (10): [very quietly] ok.

Similarly Lil' Bratz (6) says she feels 'ok' about the diabetes diet, though her mother later says that sometimes she finds not having the food she wants very difficult. Keith (6), in telling me about the time he did his own finger prick, adds 'I didn't grump or anything.' This tendency not to complain and to minimise the impact of the illness and regimen indicates a possibility that the degree of disruption to children's lives may be much greater than that which they explicitly describe. It is not surprising that when I asked Shannon (9) what her top tip for someone newly diagnosed with diabetes would be, she responded 'Be brave'.

Having outlined the challenges in children's experiences of their illness and care, in the next section I want to consider children's resolutions of these.

5.6 Children's resolutions

Children's narratives revealed responses to these challenges, at both practical and psychological levels, which centred around maintaining normality in relation to their peers. In discussing these, I use Bury's framework of 'strategy', 'coping' and 'style', where 'strategy' refers to concrete actions taken, 'style' to presentation of the illness to the self and others, and 'coping' to the maintenance of a sense of self-worth (Bury 1991).

5.6.1 Children's strategies

On a practical level, children described taking steps to minimise the disruption to their lives. For example, Lisa (9) recounts how she prefers using the remote mechanism rather than the buttons on her insulin pump to deliver an insulin bolus because it means she does not have to get direct access to her pump, which is worn under her clothes:

> Lisa (9): Cos at school we have to tuck our shirts in and it would be easier if you can just hear it [activated using the remote] rather than, like, untuck our shirt, and, like, do the pump: get it out and then put it back out. Because, like, I want to have some playtime.

Her brother Spyro (8) responds that, in turn, he finds it less disrupting to use the buttons on the pump itself to activate it:

> Spyro (8): But it does take longer. When you have the pump, it doesn't take as long as the remote.
> Katherine: The remote is quicker?
> Spyro (8): The remote is longer, because once you put how much, you need to press activate. Then you have to beep again, like 20 times, then you have to press 'Act'. On the pump all you have to do is like press 'Act' once, press 'Act' again, press 'Act' again and then press 'Act' again and then it should like go to 20 and it can go really quickly and then you press 'Act'.

Although each child's solution is different, both share the aim of minimising interruption to their day-to-day life. Likewise, when I discussed with Ruben (11) whether he would prefer an insulin inhaler over doing injections, rather than focusing on the decreased physical discomfort of using an inhaler, he raised the inconvenience and disruption of having to carry the device around with him: 'if I have to go out, I have to take it with me'. He said that, because of this, he prefers injections.

In a few instances, children recounted how in the past they have chosen being the same as others, or not being interrupted, over following their regimen. For example, as I have already described, Ruben (11) reported how sometimes he neglected to do his injections because 'I was too busy doing other things'. Likewise, Little Miss Perfect (10) described sometimes not telling the teacher when she feels low at school because she hates everyone crowding around her – though she did admit that usually her friends tell the teacher instead. And Shannon (9) recounted how once when her school held some extra exercise classes she considered not taking part alongside everyone else, because of not having any food beforehand, but then decided to prioritise joining in instead:

> Shannon (9): Someone came in [to do] exercise [classes]. But I mean, I see classes doing it and I said I wasn't allowed to do it because I didn't have anything to eat ... but I just done it.

Equally, it was clear that the desire to be the same as others sometimes motivated children to take on greater responsibility for their regimen. Emma (10) described how all her class is going away on an adventure holiday for a week and she wants to learn how to do her injections so that she can do this too. Clinicians organised a ski-trip for older children which also served as a motivation for children to learn to do their own injections.

Finally, several children revealed a particular approach to their regimen that facilitated their sense of minimising the restriction to their lives arising from the diabetes diet. Instead of adopting the clinical model where ideal blood glucose levels are around 7.5, several children revealed that they long for low levels, so that they can have a 'treat':

> Lil' Bratz (6): Ohhhh, [sounds disappointed as she views the blood glucose meter reading... she runs over to show mum] Ten!...Oh high! Too high!
> Katherine: It was too high? So what do you want it to be?
> Lil' Bratz (6): To be low...
> Katherine: Why do you like it if it's low?
> Lil' Bratz (6): Then I have a bit to eat, something to eat... crab sticks!

It may be to try to prevent children longing for unhealthily low blood glucose levels, that clinicians reported recommending that children not have sweets when they are low, though several children reported that they do save them for this time:

> Sither (8): When people have their birthdays (they give me sweets at school).
> Katherine: What do you do then?
> Sither: I ask my teacher, I don't eat it there, I take it home.
> Katherine: And then what happens?
> Sither: And then I check my blood if it's low, yeah, I get to eat it.

5.6.2 Children's styles

In terms of their identities in relation to their illness, again children preferred approaches that minimised their difference from others. Shannon (9) reported that when her school held an assembly about diabetes 'I didn't want to stand up'. When Emma (10) wrote a letter to Diabetes UK about her experiences of the illness and care, she stressed: 'I have a very busy life. I go to dance class two nights a week and also drama and choir. Diabetes doesn't stop me doing the same things as my friends.' Asked about his top tip for coping with diabetes Ruben (11) recommended 'just that sometimes, just don't think that you've got diabetes 'cos it makes it more easier. Just think that you're like other children. And then, that's what I do and it makes it easier for me.'

This desire for 'normality' also surfaced in some children's presentation of themselves and their diabetes care to me. Keith (6), George (9) and Sither (8) were very fluent and forthcoming in relation to non-diabetes aspects of their lives, for example, Keith in talking about and playing with his computer games, Sither in telling me about his pet cat; and George (9) also in relation to sport:

> Katherine: Is it a nurse or a teacher that you have at school that helps?
> George (9): A teacher… Class teacher. He supports Arsenal.
> Katherine: Is that the same as you?
> George (9): No I support Manchester United… a lot of people here support West Ham… Chelsea beat 'em!.. Chelsea beat West Ham four-one… My team beat Arsenal two-nil… They're in second place with seventy-five points now. Because if it's a nil to the person who won they get three points and if it's a draw they get one point… Chelsea [is top]. They get, they've got two points now 'cos it won, it wasn't a nil and they beat'em three more goals to one… and now they've got 91 points and Sunderland is at the bottom with 11…. Dad's got a mate called Tony who can't stand football [who supports Sunderland] … the King of Sunderland, my dad says. And then Mum's got a friend who supports Sunderland and he loves football and he also loves West Ham… I'll just put [draw] a foot with a ball 'cos I play a lot of football… I play it in school… at playtime… Three [times], one when we get to school, one after literacy and then one after numeracy.

However, they spoke about their illness and regimen in a much more reserved manner: in fact, Keith (6) was reluctant to engage about the illness at all, unless prompted by his carer, much preferring to show me his toys and games. George (9) and Sither (8) seemed knowledgeable in relation to their illness management, but were very matter of fact about this, and about their own role in their care. George even explicitly played down his knowledge about diabetes.

> Katherine: How did you learn all about your diabetes?
> George (9): I don't know. I don't really know a lot about it.

Christensen (Christensen 1998) has commented on how the access to medications afforded children with long-term illness sets them apart from other children, but it is also clear how the expertise and competence of children with long-term illness around their care distances them from their peers, and so unsurprisingly some – like the boys in Williams' study of adolescents with asthma and diabetes - will want to play this down (Williams 1999).

Yet, it seemed that in their meetings with me, many children readily set aside concerns about being the same as peers in this regard. Many described their illness and regimen in extremely lively tones, sometimes at length, emphasising their own role in their care and seeming to take great pleasure in demonstrating their competence and knowledge. Asma (5), Lil' Bratz (6), Shadow (7) and Lisa (9) were particularly noticeable in this regard:

> Katherine: Do you usually do your finger prick or does Mrs X do it?
> Asma (5): I do it!
>
> Katherine: And when you come home do you have to do anything for your diabetes?
> Lil' Bratz (6): When I come back from home I can inject my finger by myself!
>
> Shadow (7): I go to the office twice a day because, to get – because when I do playtime I do running a lot so my sugar level goes down, so I just tell my teacher, because my teachers know as well. Some of the teachers know I eat, I tell them I'm going down and, you know, when I get - before playtime, before, I just go before.

> Katherine: What does the insulin do?
> Lisa (9): It goes into our bodies, because our pancreas doesn't work properly we, it sort of, the pancreas used to give insulin, because it stops working we have to give it by ourselves. That's why the injection's there. And at bath time there's this special... like a plug, and you change it and you get the insulin off so you won't have the pump on, but you still have the insulin in your body.

This anomaly I would like to link to Goffman's description of difference and stigma as socially constructed (Goffman 1963). As I described in the opening chapters, a characteristic, such as having diabetes, that in one setting may be socially undesirable, in another; such as a diabetes support group, actually becomes a passport to membership. Because my line of enquiry modelled children's participation and expertise in their care as normal, children were able to take pride and pleasure in their competence and knowledge, despite the fact that in another setting this would set them apart from others. Further, I would like to suggest that clinicians - rather than exhorting children on one level to take responsibility for their care while at the same time colluding with parents in demonstrating a model of care with the child as passive - could also model children's competence and expertise in their care as 'normal' by engaging directly with children about their illness in the same way.

5.6.3 Coping

Children' accounts indicated the use of several techniques to maintain their sense of self-worth – what Bury has described as 'coping' – while accommodating the moral imperatives of the diabetes regimen (Bury 1991). It is striking that while for adults much of these efforts are described as relating to the accommodation of a new identity in relation to the pre-illness self (Bury 1991), in this study, children seemed to be much more focussed on minimising difference from 'healthy' peers.

One approach children took to maintaining their sense of self-worth, in respect of being 'normal' was internalising - or at least presenting themselves as having internalised - aspects of the regimen. For example:

> Katherine: Are there ever times when you can't have sweets when you would like to?
> George (9): Mmm, never.
> Katherine: No?
> George (9): No. I'm not, I don't eat … luckily I don't really eat sweets really.
> Katherine: Right.
> George (9): I don't, its … I don't really like them.

The second technique children used was adoption of an identity with similar moral imperatives to that of the diabetes regimen, for example, setting much store in being very healthy, or involved in sports or other high energy activities:

> Emma (10): After school, on Tuesday I go dancing, on Wednesday I have to help with football club… on Thursday… dancing.
>
> Lisa (9): Sometimes I just, 'cos like I want to keep healthy, like be like a good runner or something, then I have to have like good things to eat and like, so then that means like I mustn't have too much chocolate, because sometimes I have fillings, I've had loads of fillings, like three or four, so then I have to try not to eat as much chocolate.
> Katherine: So this is nothing to do with diabetes, it's about being healthy?
> Lisa (9): Yes, it's just like, you're sort of normal, it doesn't feel like you've got diabetes cos it feels like you're normal.
>
> Sither (8): [Diabetes] is nice and healthy because it keeps you healthy… It's like you be healthy, most people eat junk food…

George (9) set much store by his sporting ability -

> George (9): But – I will get a job … I'd like to do like a sporty job.
> Katherine: Yeah, something with your football?
> George (9): Yeah, or a snooker player… I'm good.

- and this facilitated his accommodation of the diabetes regimen without threatening his sense of being normal; in his top tips to someone newly diagnosed with diabetes, he described how parts of the diabetes regimen can fall in line with more enjoyable activities:

> George (9): You can do a lot, you can bring your sugar down by doing a lot of things that are good for you… Like playing about and all that.

However, there were two children in the sample, Girls Aloud (7) and Keith (6), who seemed to be struggling with ways of maintaining their sense of self-worth while accommodating the imperatives of the diabetes regimen at the same time. As I have described already, Keith (6) was reluctant to engage about his diabetes at all except when his carer encouraged him answer her questions and join in diabetes related role-play of her devising to demonstrate his understanding and familiarity with the regimen. While he seemed happy to co-operate with her around this, Keith was not happy to dwell on diabetes related subjects and hastened to move onto other activities afterwards. His grandmother's description of his reaction when he was diagnosed with epilepsy, alongside his diabetes, seemed to give some indication of his feelings behind this:

> Keith's grandmother: He just, he's gone round to his 'I'm different' again… and I say, why are you different? And he says, 'cos I have two things wrong with me.

And just as Keith struggled to maintain his sense of normality, so Girls Aloud (7) instead battled with the imperatives of the regimen. As I have already described, she was very open about her hatred of her illness and the regimen, and the daily struggle of doing injections. In one of her appointments which I observed, she quietly pointed out to her mother the page of a booklet about diabetes which read 'Diabetes does not go away', and burst into tears when the DSN recommended she increase her insulin doses. This is not to claim that other children in the sample did not experience difficulties. For example, George's mother had described how he had recently come out of a long spell of having to attend hospital regularly for diabetic ketoacidosis and Ruben had had a period of skipping several insulin injections. However, both seemed to be developing ways of maintaining their sense of normality in the face of the imperatives of the regimen, whereas Keith and Girls Aloud still seemed to be struggling with this. This chimes with quantitative research that suggests that adjustment to long-term illness may be especially hard for those living in very stressful circumstances (Amer 1999; Bradley & Gamsu 1995). Both Keith, and his grandmother, with whom he lives, had, until recently, endured on-going domestic violence from his grandfather. When I visited Girls Aloud's household, the atmosphere was heavy with her mother's despair at trying to cope, on her own, with four children with multiple illnesses, living in flat with chronic damp, and heating problems. As I have already described, Shannon (9) pointed out how dealing with diabetes requires great bravery: finding the psychosocial resources for this in situations of enormous stress is unlikely to be easy.

In the next section I want to move on from thinking about children's responses to their illness in terms of their day to day behaviours and identity to considering children's learning and understanding about their illness.

5.7 Children's learning and understanding of their illness

Findings from the study support theories which present children's learning as a gradual, cumulative process centring around children's immediate physical and social experiences (Christensen 2000; Christensen 1999; Alderson 1993) - for example, Trunks (6) doesn't know the name for an insulin cartridge, but, from his day-to-day social experiences, he does know what to do with it:

> Katherine: [Looking at photograph] What's in the big, blue box?
> Trunks (6): You have to put it in the [injection pen] if the other one's finished.
> Older brother (not in study): It's the insulin.

5.7.1 Children's social learning

Children's good knowledge of their regimen of blood glucose tests and insulin injections seemed to be based in their social experience of these as taking place within the context of other daily events of their lives.

> Marjan (5): Now Teddy needs to go to bed. First he has his injection. (Puts strip in blood glucose meter) (sic).

> Katherine: When does Teddy have [his blood tests]?
> Girls Aloud (7): In the morning at 8 o'clock and before you eat lunch and 5 o'clock and before you go to bed.
> Katherine: ... And what about the injection, when does he have to have that?
> Girls Aloud (7): He has to have it before - after his test and ... then he does it 5 o'clock after this.

It seemed that at least two children, Asma (5) and Little Miss Perfect (10), at either end of the age spectrum in this study, believed diabetes to be caused by 'too much sugar' or 'junk food' (Little Miss Perfect, 10) and it may be that the pivotal role of children's social experiences of the illness and regimen in building their understanding of the illness - specifically, restricted intake of these kinds of food - explains the persistence and power of this interpretation.

5.7.2 The importance of physical experiences in children's understandings of illness

The language children used to describe their diabetes and its care drew attention to the centrality of their physical experiences in understanding their illness and the regimen (Christensen 1999; Christensen 2000). For example, I have already described how, in speech, many children – not just younger ones – grouped their experiences of finger pricks and insulin injections together, by virtue of the physical experience of having the skin punctured, common to both; and how, as described above, when I asked Lil' Bratz (6) what she would discuss if she met another child with diabetes, she referred both to her social experiences of a restricted diet, and to her physical experience of her 'pricks'. Children also often referred to their illness itself - as well as the regimen - purely in terms of their physical experiences:

> Girls Aloud (7): Sometimes I feel dizzy at home and at school.
>
> Katherine: What about when you do games or PE at school?
> Sither (8): I don't feel my shake, I don't feel it.
>
> Lisa (9): When we went to nursery I remember once I felt wobbly and I had to sit down at the fence

> Emma (10): when I was in year 3 I used to fall asleep in class… I kept going shaky and I didn't know.
> Emma's mother: Ever since she was four she's always called a hypo 'going shaky'.

Children's narratives also indicated their sensory, in particular, visual experiences as especially important. On several occasions children spontaneously pointed out the how the testing kit or insulin pen I brought with me when visiting them at home differed in appearance – especially colour – from their own:

> Katherine: [Shows injection pen] Do you have one like this?
> Asma (5): No… it's green.
>
> Katherine: [Shows finger pricker] Do you have something a bit like this?
> Asma (5): No.
> Katherine: What colour's your one?
> Asma (5): Grey and shiny.

In both these comments it seems Asma's (5) perception of the finger pricker is as much rooted in its colour as in its function; and, equally, below, for George (9), the colours of his injection pens are vital markers:

> George (9): The bedtime's the purple case, the morning and afternoon's one's red, but in the middle of the afternoon one it is blue, and its blue and yellow in the middle.

5.7.3 Learning bio-medical models

Christensen (Christensen 2000) has described how children begin to learn bio-medical models of illness by making links between these and their experiential understandings. A common example in this study was when children made the link between the physical experience of hypoglycaemia and an abstract understanding of this as a low level of blood glucose:

> Shadow (7): when my sugar is low … I know the feeling, whsssh, and I can feel the whssh thing.
>
> Sither (8): Sometimes when I'm shaking… it means my bloods low.

> George (9) tells me, 'When I'm really, really starved.... I go and check my blood.
>
> Katherine: How do you know when you're going low?
> Spyro (8) : I feel wobbly ...
>
> Katherine: How can you tell when you've got a hypo, can you -
> Shannon (9): Go shaky.
>
> Ruben (11): When I'm, my, like, sugar's low, I start feeling dizzy.

Even some of the youngest children were able to make this connection – for example, when I tell Asma (5), during role play with a doll, '[dolly] feels a bit wobbly, do you know why she might feel a bit wobbly?' she replies 'Her sugar level's down'.

5.7.4 Learning over time

Children's narratives indicated that learning the connection between physical sensations and specific aspects of the bio-medical model of diabetes takes practice. For example, most children were confident about identifying the more common experience of hypoglycaemia. However, apart from Ruben (11), the oldest child in the sample, it tended to be only children with very long experiences of living with a diabetes diagnosis who were confident of recognising the less frequently occurring hyperglycaemia: Spyro (9) via feelings of nausea, Lisa (9) by tearfulness, and Ruben (11) by feeling hot. Shadow (7), diagnosed about two years ago, reported that that sensations of both high and low blood glucose levels currently feel 'the same' for him. Likewise, Little Miss Perfect (10), also diagnosed about two years ago, said that she can only feel hypoglycaemia 'sometimes' and hyperglycaemia not at all, though her brother, Trunks (6), four years her junior, has had diabetes for longer than her, and can recognise both.

As I have already described, rather than absorbing bio-medical models as complete entities, children seemed to gain a step-wise understanding of each of the different aspects of these via their own specific social experiences. For example, when I ask George (9) why he can't eat sweets he seems unclear about the impact of food on blood glucose levels:

> George (9): Because, if I eat sweets, my blood [pause], my blood [pause].

Yet later, he draws on his own experiences to tell me that 'I have to have my meal... because [I] might go low.' Similarly, when I ask Spyro (8), what insulin does, he says he does not know, but, later, drawing on his own experiences, he says 'If you eat like too many sweets and like don't do the [insulin] pump, you'll go really high'.

5.7.5. Adult support of children's learning and understanding

Some carers demonstrated an understanding of children's learning as experiential and context-based when they used prompts relating to children's day-to-day experiences to help extend or reinforce children's understandings. For example:

> Katherine: Now Asma's doing Teddy's finger prick and she's wiping the blood carefully under the strip... What shall we do for Teddy if it's 3.4?
> Asma (5): I don't know.
> Asma's mother: What do I say to you if your sugar levels 3, 2, 1?
> Asma (5): Insulin.
> Asma's mother: No.
> Asma (5): It's low.
> Asma's mother: It's low, so what are you meant to have?
> Asma (5): Lucozade.

These techniques may also be useful to clinicians in scaffolding children's learning. I observed Ruben's DSN using a similar technique to help Ruben, when he skipped some insulin injections, learn from his physical experiences of illness at that time, of the importance of doing his injections. She questioned him first about how he felt when he did not take his insulin and then again about how much better he felt when he did.

5.7.6. The importance of relevance

Unsurprisingly, children seemed to retain those understandings with the most immediate significance and meaning in their lives. For example, Spiderman's (4) mother reported that he already realises that the outcome of his blood glucose test determines whether he can have a treat. Likewise, as already described above, Lil' Bratz (6), showed a clear understanding of blood glucose meter readings, arising out of her desire for a low result. Thus, children were most confident giving accounts of their illness that related directly to their own experiences. Their answers to questions which drew directly on an abstract bio-medical model without reference to experiences children could recognise from their own lives, were less confident and specific. For example, Ruben (11) tells me in detail about his decision-making about pre-bed snacks in light of his blood glucose levels:

> Ruben (11): If it was seven before I went to sleep I will have something with sugar because it will make it go high, but that would be good because at night it goes down, then I'll be going down and I'll be normal, something like eight.

Yet previously, when I asked him the more general and non-context based question about 'why does it matter what you eat' he said that he didn't know. This suggests that if clinicians wish to engage meaningfully with children about their illness and regimen, discussion and questions which relate to the specifics of children's physical experiences and day-to-day routines may work better than talk relating to a generalised, abstract bio-medical model.

5.7.7 Step-wise and cyclical processes of learning and taking responsibility for practical tasks

In the final part of this section I want to look specifically at children's learning of practical tasks, such as doing insulin injections or delivering an insulin bolus from the pump. Children were explicit about the importance of watching parents in this:

> George (9): I've seen what my mum does and all that.
>
> Katherine: How did you learn how to do it?
> Emma (10): I saw my mum...
> Katherine: And who know how much insulin to put in?
> Emma (10): Me or my mum.
> Katherine: How did you find out about that?
> Emma (10): By watching my mum again.

> Katherine: And how did you learn [to work the pump]?
> Spyro (8): I just got used to it – I always looked how he did it so I learned.

Children's descriptions were also characterised by cyclical patterns of trying injections once or for a short time and then relinquishing this again before building up to take greater responsibility. Often one particular injection site was favoured within this. For example, Zak (8) and George (9) had both had experiences of doing their own injections in their leg, but did not yet do this on a regular basis. Likewise, Sither (8) reported, 'I used to do my leg, it's easy in my leg… I stopped it now because I keeped on doing it in there' (sic). Emma (10) described having done her own injection several times a week over a 6 month period – only in her belly; and Shannon (9) doing her evening arm injections. That children's learning takes place over time may explain why the process seemed so opaque to some:

> Katherine: How did you learn how to do it? How did you know?
> Lil' Bratz (6): I don't know.
>
> Katherine: How did you learn how to know how to do your injections?
> Shannon (9): I don't really know

Lastly, from children's accounts it seemed carers and children often divided up practical tasks such as the blood test or insulin injection into a series of small steps for which children and carers variously took responsibility. For example, using Teddy as a model, Asma (5) shows me how she does her finger prick and doses the test strip, but reports that, currently, it is her mother who checks the resulting reading on the meter:

> Katherine: What do these numbers mean on here?
> Asma (5): I don't know.
> Katherine: Do you tell your mum or write the number down?
> Asma (5): I don't do it yet.

'Yet' reveals her assumption is that in the future she will take over responsibility for this aspect of the regimen. Likewise, in discussing his insulin injections, Shadow (7) volunteers how he and his mother share out different stages of the process:

> Shadow (7): I don't really do the insulin I haven't learned yet. But I know how to get it ready, all she has to do is just rip the top bit … I just shake it, I just open the lid and I just give it [to her].

Thus, just as children did not absorb bio-medical models as complete entities, but gained a step-wise understanding of each of the different aspects of these via their own specific social and physical experiences, so they also seemed to build up their experience of carrying out the different stages of completing practical tasks gradually over time.

5.8 Children's minority ethnic status

Although social and economic exclusion remains a defining experience for many people from minority ethnic backgrounds (Karlsen & Nazroo 2002; Spencer 1996), and I discuss this further in the next section, what I observed and heard from children and parents also flagged up some important issues arising out of cultural and linguistic difference. The most striking of these was the problems for carers who spoke a limited amount of, or no, English – which, of course, given the joint nature of care, indirectly created problems for children also. A particular issue here seemed to be that precedents set at the time of the child's diagnosis had continued to define practice beyond that time without clinicians double checking with families about their wishes. For example, Marjan's sister explained that she was happy to act as an interpreter during the difficult time of Marjan's diagnosis but that on-going clinic appointments clashed with her studies and so were more problematic. Likewise, perhaps because of her partial competence in speaking English, Girls Aloud's mother had not been using an interpreter in clinic appointments. However when I approached her about the project, she requested an interpreter for my visits to her home, and in those meetings also expressed a desire to have an interpreter in clinic appointments.

A further problem seemed to be ambivalence about using a relative stranger as an interpreter. Girls Aloud's mother reported that she was not happy that when an interpreter did finally ring her to make plans for the appointment, she was unwilling to engage on a personal level with her about her background and what she would look like when she met up with her. Some people who are in the UK and do not speak English come from war zones and places of conflict. Whether this distrust derived from tensions between different groups, or had its roots simply on a personal level, I was not clear, but in this case Girls Aloud's mother decided to dispense with interpreting services altogether.

Moving on from linguistic to cultural issues, it was clear, from one small example, that the disruption caused by the illness regimen may be compounded when it restricts participation in activities in the home particularly important to maintaining ethnic identity. Marjan's mother spoke of Marjan's sadness at not being able to have Somali spaghetti along with the rest of the family. Described only in passing, I am not clear whether Marjan is upset specifically because of the symbolic aspect of the meal as part of Somali identity, or whether her distress is part of a general sense of exclusion from the family meal; but that her mother chose to mention this particularly in relation to the Somali spaghetti dish as opposed to any other food, indicates the possibility that it is the regimen's restriction of participation in an identity-related activity that causes disquiet. Interestingly when I raised this issue with clinicians, I was told that Marjan's mother must have misunderstood the regimen, since it should not restrict Marjan's consumption of savoury foods.

Before moving onto discussing the impact of poverty on children's experiences, I want briefly to consider the issue of widespread assumptions about strong family support in minority ethnic groups. Certainly in this study it was only in Somali families – Zak's and Marjan's – that children spoke of, and I observed, sibling involvement in the maintenance of children's regimen. Zak described his brother reminding him about his snack, and Marjan of her sister doing her insulin injections; and two out of the three times I met Marjan at the clinic, it was her 18 year-old sister who was accompanying her, rather than her parents. Equally, however, Sither, also from a Somali background did not describe his older brother as having any role in care at all. Likewise the common assumption that people with minority backgrounds will have a strong support network based in the extended family did not bear out routinely in the work. The narrative and demeanour of Girls Aloud's mother spoke eloquently of the difficulties she experienced trying to cope as a single mother in poor housing with little social support; and while it was clear from the accounts of other children with minority backgrounds that their extended families did play an important part in their day-to-day lives, this was also apparent in the narratives of several children from White backgrounds, such as Keith and Spiderman, who described the prominence of uncles, aunts and grandparents in their lives.

While the examples above around the effect of cultural and linguistic difference on care are important, I would like to argue that it is the interaction of cultural or linguistic difference with the poverty and social exclusion associated with minority ethnic status (Karlsen & Nazroo 2002; Spencer 1996), rather than cultural difference per se, that seemed to impact most significantly on children's experiences of their illness and care. Economic disadvantage – in particular poor housing and the stress associated with this – seemed to compound the disruption in children's lives arising from the illness and regimen and limit enjoyment of those aspects of their lives relatively untouched by the regimen. For example, several children were sharing a bedroom with more than one other sibling and reported that managing their diabetes is hard 'when my brother and sisters wake me up in the night' (Zak, 7). Others lived high up in blocks of flats, far from any outside space where they can run and play or ride bicycles. Of course, this did not mean that children did not get access to such spaces, but rather that carers had to set aside special time to accompany them to public parks away from the home, so that, despite the fact that regular exercise is an important aspect of good diabetes care, opportunities for this were less frequent – for example, as Girls Aloud describes, only at the weekends. Three children were living in homes in strikingly bad states of repair; Girls Aloud, as I have already described, with extensive damp mould throughout her home:

> [Extract from fieldnotes]: The flat has boarded up fire places; the window on the door is boarded over, taped up and painted over; and it is very hot, with the windows wide open. Later Girls Aloud's mother explains this is what the landlord told her to do about the chronic damp infesting the flat. She shows me where she has painted over it but it just comes back: the top of the sitting room walls and ceiling and bathroom are all covered in damp mould.

Girls Aloud herself reported 'I hate my house because it has dampness there'.

At the opposite extreme, the economic advantage of Lisa and Spyro's family – whose father was in a professional job - seemed to facilitate their surmounting, at least to some extent, the restrictions and disruption caused by the illness and its care. For example, the children managed their diabetes via insulin pumps rather than injections, and moderated their insulin intake in relation to their food, freeing themselves up from regular snacks and stringent dietary restrictions. As Lisa (9) described it, having the pump means '...it's just like, you're sort of normal, it doesn't feel like you've got diabetes 'cos it feels like you're normal.' Further, the children had unlimited access to outside space for exercise and play around the family home, and described how 'we're going to get an extension on our house' so that the frustration of not being able to go for sleepovers at other people's houses might be minimised by having friends over to stay at their house instead.

I do not mean to suggest by this that all families living in relative economic disadvantage seemed to be struggling with management of the illness and its care. Children and carers showed great resourcefulness in coping with the impact of diabetes in their lives. However, it is clear, from comparison of the experiences of, for example, Lisa and Spyro, with Girls Aloud, that the accumulated stresses of poor housing and low social support in Girls Aloud's family left relatively few psychosocial resources for grappling with the disruption of living with diabetes and its regimen.

5.9 Summary of findings

Children described disruption across physical and psychosocial and emotional spheres as a result of their illness and regimen. Their narratives focussed especially on their experiences of care: the relentlessness of the regimen of different needles for blood tests and injections, and how this, and the restricted diet, interrupts their day-to-day activities and sets them apart from peers. It seemed that children may bear an emotional toll in terms of on-going efforts to make the 'right' decisions in relation to their care, and/or conflict with carers about the regimen, and, for some, fears about the long-term consequences of their illness for their health. Finding the psychosocial resources to meet these challenges may be particularly difficult for those experiencing stress as a result of family social and economic exclusion.

Children described taking steps to minimise the disruption to their lives and valued identities that allowed them to accommodate the moral imperatives of the diabetes regimen while at the same time maintaining their sense of being the same as others. Yet, the way children presented themselves and their illness differed across settings. Children described valuing normality very highly in peer group settings, yet, to varying degrees – possibly girls more readily than boys - were willing to be explicit about their unique understanding of diabetes and its care in the context of meetings for the study.

Findings from the study support theories which present children's learning as a gradual, accumulative process centring around children's immediate physical and social experiences (Christensen 2000; Christensen 1999; Alderson 1993). Children with the longest experiences of illness – not always the oldest children - tended to be the most adept at making connections between bio-medical models and their social and physical experiences.

In the next chapter I set out a synthesis of these findings with findings from studies identified in the review.

Chapter 6: Findings from review

In this chapter I set out findings from a synthesis of studies on children's experiences of children with asthma and diabetes to address my two review questions:

- 'What have children with type 1 diabetes or asthma told us about their experiences of their long-term illness and its care?';
- 'What are key aspects of patient-centred care for school-age children and levers and barriers to its achievement'.

As I have described, I will not set out findings from my first attempt at synthesis using an aggregative thematic approach as this produced a detailed summary, which, though useful as an overview and as part of my familiarisation with the data (see Appendix 13), was less helpful in terms of answering my research questions. I reflect on learning from these processes in the Conclusions chapter.

In the course of this chapter I refer to review studies' methodological quality. These judgements are based on the criteria set out in Chapter 4, and therefore refer to methodological quality solely for the purposes of this review.

6.1 Overview of the studies

The review comprised 13 descriptive studies of participants' views and experiences - plus my own fieldwork study - carried out in the UK or USA. No studies from other countries included in the search strategy fell within the inclusion criteria. Details of methods and findings are tabulated in Appendices 11 and 12. Most collected data from children only, though some included carers and teachers. Most set out data on participants' experiences as interesting in their own right, though a few set these out alongside quantitative data, for example on children's glycaemic control, illness knowledge or performance in psychological tests. Seven authors sampled children living with asthma, five sampled children living with diabetes (six including my fieldwork) and one sampled children with asthma and with diabetes. Most studies recruited children from clinics, though several used asthma camps, support groups and schools. All studies used one-to-one or group discussion to gather children's views.

With the exception of one early project, published in 1983, papers on children's experiences of asthma are concentrated between 2002 and 2005, perhaps a response to concerns that came to light in the second half of the 1990's around under-diagnosis and treatment of the illness amongst children, particularly in minority ethnic populations (Duran-Tauleria et al. 1996; Sturdy et al. 1996). Conversely, publication dates of diabetes studies seem to indicate an ongoing interest in the experiences of children with this illness sustained over more than a decade: several studies appeared in the early 1990's, again at the end of that decade, and once again in 2003-5. See table 6.1 below for details of studies grouped by characteristics discussed in this section.

Location	Illness	Sample: ethnicity	Sample: age	Researcher discipline
UK: Ireland 1997, Miller 1999, Sutcliffe 2003, my fieldwork 2006	**Asthma:** Walsh 1983, Ireland 1997, Pradel 2001, Meng 2002, Koinis Mitchell 2003, Dell Clark 2003, Boyle 2004, Rudestam 2005	**At least half MEG** Pradel 2001, Koinis Mitchell 2002, Meng 2002, Boyle 2004, Rudestam 2005, my fieldwork 2006	**Median <8 years:** Dell Clark 2003, Sutcliffe 2003, my fieldwork 2006	**Social Science:** Dell Clark 2003, Sutcliffe 2004, Rudestam 2005, my fieldwork 2006
				Nursing: Walsh 1983, Spezia 1991, Ireland 1997, Miller 1999, Meng 2002, Boyle 2004
USA: Walsh 1983, Spezia 1991, Zahorik 1991, Pradel 2001, Meng 2002, Dell Clark 2003, Koinis Mitchell 2003, Nabors 2003, Boyle 2004, Rudestam 2005	**Diabetes:** Spezia 1991, Zahorik 1991, Miller 1999, Nabors 2003, Dell Clark 2003, Sutcliffe 2003, my fieldwork 2006	**Predominately white:** Walsh 1983, Spezia 1991, Zahorik 1991, Ireland 1997, Miller 1999, Nabors 2003, Dell Clark 2003, Sutcliffe 2003	**Median > 8 years:** Walsh 1983, Spezia 1991, Zahorik 1991, Ireland 1997, Miller 1999, Pradel 2001, Meng, 2002 Koinis Mitchell 2003, Nabors 2003, Boyle 2004, Rudestam 2005	**Other clinical:** Pradel 2001, Koinis Mitchell 2003, Nabors 2003
				Not known: Zahorik 1991

Table 6.1 Studies grouped by background characteristics*

**for the sake of clarity I have abbreviated study references to the date and name of the first author only. For the same reason, when I discuss studies in the text, I identify them by the first author only, for example, Sutcliffe's study (Sutcliffe et al. 2004)*

Studies of children's experiences of asthma are almost entirely North American, in many cases with samples of children predominately from minority ethnic backgrounds, again, perhaps related to concerns about the under-diagnosis and under-treatment of asthma in children with minority ethnic backgrounds (Duran-Tauleria et al. 1996; Sturdy et al. 1996). By contrast, studies of children's experiences of diabetes are both USA- and UK-based, though carried out almost entirely with samples of children predominately from white 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).

Most studies, across illnesses, were carried out by authors with a nursing background. This is particularly true of earlier studies and may relate to the perception that concerns about patient experience fall within the nurse's remit. It may be that there is a relationship between nursing's secondary status in the medical hierarchy (Friedson 1970) and the low priority afforded issues of patient experience compared with clinical issues. Between 2002-3, several papers were published by psychologists and a pharmacist, 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, perhaps reflecting the growing sociological interest in children's experiences described in Chapter 2.

It is only social scientists who have studied samples of children with a median age of seven years or younger. This may be related to sociological views of childhood, which incorporate an assumption of children's competence across ages. This indicates how one's views of children - unsurprisingly - affect one's ways of engaging with them. This is an idea I explore further in later parts of this chapter.

6.2 Key themes

As I described in the methods section, I carried out a second thematic analysis, this time conceptualising patient-centred care as care that engages with children's day-to-day experiences of managing their illness. I searched for themes relating to what, in the view of authors or myself helped or hindered children manage their day-to-day illness. I noticed that this seemed to relate a) to the child and his/her beliefs/competencies; or b) to illness; or c) the regimen; or d) to wider environmental influences and marked these categories on my tabulations of themes from each study, (see appendix 14). Finally I grouped themes under key headings, as set out below.

a) The illness

- Causes children physical and emotional pain, including feeling different from peers

b) The intervention

- Causes children physical and emotional pain, including feeling different from peers and impinging on valued free time
- Structures at a meso-levels (for example in schools) and macro-level (for example socio-economic stresses) especially in MEG populations, can exacerbate this
- Sometimes the intervention does not work (asthma)

c) Children

- Have good empirical knowledge about their illness and care even at young ages (though this can grow with experience)
- Working in partnership with carers, can take on-going responsibility for their care even at young ages (this can grow with experience)
- But sometimes don't follow their regimen because...
    - they don't understand it
    - they don't feel they can control the illness
    - the regimen is more disrupting physically or psychosocially than the illness itself

d) What might improve children's day-to-day experiences of managing?

- Better interventions - quick, effective, painless, inconspicuous and convenient interventions that allow children to get on with their lives
- Better support - carer support (practical and emotional); peer support (practical and emotional); teacher support (practical) and better systems in schools; positive feedback in clinic and other attempts to improve self-confidence; fewer socio-economic stresses; use of play, ritual, stories, humour, camps

Better education in relation to disease management: accessible, empirical information offered on on-going basis.

6.3 Relationships within and between studies

Building on Popay and colleagues' guidance on tools for examining the influence of study heterogeneity on findings, I set out below a discussion of where different studies brought similar or different findings to each of the themes outlined above. Where findings across studies overlapped I was able to explore what 'translation' of these across studies added to the emerging synthesis (Popay et al. 2006). I was also keen to explore differences or similarities in findings across different populations (by illness, ethnicity or age), methodological quality of studies, and relating to researchers' divergent attitudes to and understandings of children and childhood (Popay et al. 2006).

6.3.1 The illness can cause children pain across social and emotional as well as physical spheres

In Rudestam's methodologically strong study, with an ethnically mixed sample of 26 children both with and without asthma, those with the illness described 'wheezing', tightness in the chest, breathlessness, nausea, and feelings of fear, powerlessness, and vulnerability in relation to their condition (Rudestam et al. 2005). These match findings in studies, with similar samples of children with asthma, though judged less methodologically strong. In Pradel's study, carried out with an ethnically diverse sample of 32 children with asthma, participants describe similar physical symptoms (Pradel et al. 2001); and in Meng's study with an ethnically diverse sample of 28 children, participants describe worry about shortness of breath and seasonal symptoms (Meng & McConnell 2002). In Boyle's study with 19 African-American children with 'breathing problems', participants recount similar physical and emotional stresses, and a fear of dying from their condition (Boyle et al. 2004). Boyle argues that the 'upper-airway descriptors' which children in her sample use to describe their symptoms are different from the 'lower-airway or chest-wall symptoms' described by white children, which may therefore make it difficult for white clinicians to diagnose African-American patients (Boyle et al. 2004).

Children in other studies use both 'upper-airway' and 'lower-airway' descriptors, but authors do not identify children's ethnicities in relation to these.

In Walsh's methodologically strong study, with 61 children with asthma, in this case mainly from white backgrounds, children again describe the same physical and emotional stresses, including fear of dying (Walsh 1983). This chimes with findings from Dell Clark's less methodologically strong study, which included 23 younger (on average), mainly white children, and where, drawing on findings about how children may hide difficult experiences from adults (Bluebond-Langner 1978), the author suggests that parents are not routinely aware of the very great extent of the child's fear of asthma (Dell Clark 2003).

Ireland's methodologically stronger study with 10 children with asthma (ethnicity not stated), also reports that some children feel powerless in the face of their illness (Ireland 1997). Findings differ from those of the other asthma studies in that Ireland describes how children's experiences of physical symptoms can make them feel different from other children (Ireland 1997).

In my fieldwork study with 17 younger (on average) children from diverse ethnic backgrounds with diabetes, children described being faint, nauseated and/or dizzy from glucose imbalances, and they felt this marked them out from their peers (Sections 5.3 and 5.4). They also described fear about the long-term outcomes from their condition (Section 5.5). Miller's study with six children (ethnicity unknown) with diabetes also found children worried about long-term health outcomes (Miller 1999). She reported the confusion and disbelief children experience when they receive their diabetes diagnosis (Miller 1999). Dell Clark's less methodologically sound study, which included 23 younger (on average) children with diabetes mainly from white backgrounds, found children to report dizziness from low blood glucose levels, and fear about this, especially when it happened at night (Dell Clark 2003). Zahorik's study, with 26 children mainly from white backgrounds, found children expressed some concern about long-term health outcomes but felt these to be controllable via proper adherence to the regimen (Zahorik 1990).

That the illness causes physical, emotional and psychosocial stress to children is borne out by evidence described above, from both methodologically stronger and weaker work, and across populations of younger and older school-age children across a range of ethnic backgrounds. While it is, of course, unsurprising that children across the two illnesses experience different types of physical symptoms, it seems that the emotional impact of the illness on their lives may vary. Those with diabetes may be more fearful of health outcomes in the long-term, though, possibly – and this may need further investigation since it arises from a study less methodologically sound for the purposes of this work – children with diabetes may have a sense of being able to control long-term health outcomes via strict adherence to the regimen. By contrast, it seems children with asthma may live with an immediate and on-going fear of death, and a sense of powerlessness in the face of their illness. These fears may be greater than parents and carers realise – though, again, this last finding arises solely from a less methodologically sound study and so requires further investigation.

6.3.2 The intervention can cause children pain across physical, emotional and social spheres

Rudestam found children to resent the limitations imposed by the asthma regimen on their time spent outside and in physical activity (Rudestam et al. 2005). This chimes with findings from Walsh's study with a sample of children mainly from white backgrounds (Walsh 1983), and also findings from the less methodologically sound study by Pradel - though Rudestam explores the issue further to discover that children also resent the limitation this then places on time spent with friends (Rudestam et al. 2005). In another less methodologically sound study Boyle describes limited physical activity as particularly difficult for the sample of African-American children in her study, for whom, she argues, sport is an especially important activity (Boyle et al. 2004).

Children in Rudestam's study also describe resenting the interruption caused by having to go to hospital (Rudestam et al. 2005). In Meng's less methodologically sound study it is suggested rather that children dislike hospital because of worrying about what will happen when they are there (Meng & McConnell 2002).

Findings across the other less methodologically sound studies include that children with asthma worry about running out of medicines and missing school (Meng & McConnell 2002); though children in Pradel's study describe that it is having to catch up on missed work, rather than missing school, per se, that concerns them (Pradel et al. 2001). Three studies report children disliking the taste of their asthma medicines (Boyle et al. 2004; Koinis Mitchell 2003; Pradel et al. 2001), and Pradel found that medicines make some children feel sick (Pradel et al. 2001). She further found younger (7 year-old) children to report the regimen of regular medicine-taking as intrusive (Pradel et al. 2001). In Koinis Mitchell's study of 28 children - again, mainly from ethnic minority backgrounds – it was the interruption caused by having to avoid triggers that children resented (Koinis Mitchell 2003). Boyle reports children feeling sad about not being able to have pets (Boyle et al. 2004).

The mainly white children in Walsh's study also reported feeling sad about not being able to have pets (Walsh 1983). Further they described how they disliked others watching them use their medicines (Walsh 1983). Dell Clark's less methodologically strong study, also mainly with white children, though in this case including younger (on average) children, again found children to dislike taking medicines in front of peers, to report them as unpleasant tasting and describe feeling sad about not being able to have pets (Dell Clark 2003).

Children with diabetes also seem to suffer across physical, emotional and psychosocial spheres as a result of their regimen. In my own fieldwork study with an ethnically diverse sample of younger children, some suffered considerable physical and emotional stress as a result of the pain of injections; many found the relentlessness of the restricted diet and the regimen of tests and injections disruptive – including the way they felt these marked them out as different from peers (Section 5.4). This chimes with findings from Spezia and Miller's studies – both mainly with white children - that the diabetes diet is problematic (Spezia 1991) and the regimen as a whole inescapable, relentless, boring, time consuming and intrusive (Miller 1999). Interestingly, within this, Miller found children to flag up the pain of blood tests, rather than injections, as problematic (Miller 1999). In terms of psychosocial stress, children in Sutcliffe and colleagues' study were defiantly positive about how diabetes does not stop them being 'normal' (Sutcliffe et al. 2004), just as in Spezia's study, they were adamant they were the same as other children, apart from having to follow the diabetes regimen (Spezia 1991). This corresponds with findings in Miller about the importance of being the same as peers (Miller 1999); and in my fieldwork that it is the regimen that marks one out as different (Section 5.4).

These findings from the stronger diabetes studies correspond with others from less methodologically sound work. Zahorik reports children to dislike the diabetes diet, the interruption caused by regular tests and injections, having to have snacks in front of peers; and to defend their 'normality' in relation to others who do not have diabetes (Zahorik 1990). Dell Clark also describes children to dislike the pain of the injections, the restrictions of the regimen of tests and injections, and the diet (Dell Clark 2003). Once again, drawing on findings about how children may hide difficult experiences from adults (Bluebond-Langner 1978), Dell Clark suggests that parents and carers are not aware of the extent to which children find their injections painful, nor the extent to which parental attempts to make up for the restricted diet fail to compensate the loss children feel in relation to this (Dell Clark 2003).

This evidence suggests that children across illnesses, ages and ethnicities experience their regimen as restrictive and disruptive across different spheres of their lives: physical (unpleasant tasting medicines, painful injections); emotional (feeling sad about limited time playing sport or not being able to have 'unhealthy' foods); and social (less time with friends, feeling defensive about their 'normality' because of the regimen). It may be that parents and carers are not aware of the extent of children's suffering in this regard and that children from backgrounds where activities limited by the regimen are an important part of identity may suffer disproportionately – though these last two findings are from studies less strong for the purposes of this work and may need further investigation.

6.3.3 Structures at a meso-level (for example in schools) and macro-level (for example socio-economic stresses) especially in minority-ethnic populations, can exacerbate disruption to children's lives

Rudestam describes how children with asthma feel more vulnerable in environments which contain asthma triggers and points out how the polluted, inner-city environment in which children are living exacerbates their illness (Rudestam et al. 2005). Authors of a number of methodologically weaker studies reflected on the possible impact of other socio-economic stressors on children's lives. Boyle (Boyle et al. 2004) suggests that the extreme language used by some African-American children to describe their symptoms may be related to a spontaneous association of asthma with death, in her view arising out of experiences of racism. Meng reflects that single parenting, low income and job demands may limit the extent of parental support for children in her sample (Meng & McConnell 2002); and Koinis (Koinis Mitchell 2003) that children's management may be affected by stressors such as low family income, cultural dislocation and lack of access to good health care – though authors do not explore these issues in any more detail than this. In my fieldwork study with a diverse sample of children with diabetes I also found that economic disadvantage, in particular poor housing and the stress associated with this, seemed to compound the disruption in children's lives from their illness (Section 5.8.2). Two children living in very stressful home environments seemed to find it particularly hard to incorporate the regimen into their day-to-day lives.

In Meng's methodologically weaker study with an ethnically diverse sample of children, children reported their biggest worry about asthma at school to be access to medicine during gym (Meng & McConnell 2002). In Koinis' study with a similar sample – also methodologically weaker - children described feeling confident in managing their asthma at school when they knew they could ask a nurse or teacher for help (Koinis Mitchell 2003). In her methodologically strong study, with mainly white children, Ireland describes how access to medicine in school could influence a child in making decisions about controlling their asthma (Ireland 1997) and in both Sutcliffe and colleagues' and Miller's study with a similar of sample of children, but with diabetes, and in my fieldwork study with diverse group of children with diabetes, it was found that systems in schools could exacerbate children's sense of difference from others (Miller 1999; Sutcliffe et al. 2004) (Section 5.4.5 of my fieldwork report). Nabors study of mainly white children with diabetes focussed specifically on children's experiences of managing their care in school and found children wanted teachers, nurses and friends to improve their knowledge of diabetes, and diabetes supplies and medical support to be routinely accessible (Nabors et al. 2003).

In conclusion it seems authors of both stronger and weaker studies, with samples of older and younger children from predominately minority ethnic backgrounds, reflected on the impact of socio-economic stressors on children's management of their illness, including the impact of poor housing and local environment, low income, poor health care, and 'cultural dislocation'. Authors of both stronger and weaker studies across ethnicities describe how systems in schools can make it harder for children to manage their illness due to lack of access to medicines or appropriate support, or systems that exacerbate children's sense of difference from their peers.

6.3.4 The intervention may not always work

Boyle found children to report that their asthma medicine is not always effective in reducing symptoms (Boyle et al. 2004). Pradel found the same with the 12 year-old children in her sample, those who tend to use their medicines autonomously, but not with 7 year-old children, who tended to refer to parents or carers when using medicines (Pradel et al. 2001). Though these are both methodologically weaker studies, the trustworthiness of the finding is increased because of its appearing more than once. Yet Pradel also reports that children did not distinguish between their preventative and rescue medicines, which raises the possibility that while there may be a problem with the effectiveness of medicines, the problem may also arise out of children mixing up the different types of medicine (Pradel et al. 2001). The fact that medicine ineffectiveness is particularly reported by children who medicate autonomously, compared with those who are supervised, suggests that this may be a factor.

6.3.5 Children have strong experience-based knowledge about their illness and care, and, alongside carers, can take on-going responsibility for their care; responsibilities and learning may grow, though not linearly, with experience/age

Authors of studies of children with asthma report concern that children do not know the proper names of their medicines (Koinis Mitchell 2003; Pradel et al. 2001; Walsh 1983), and that they cannot draw an adequate bio-medical diagram of the lungs (Walsh 1983). Yet, across ethnicities, ages, and in weaker and stronger studies, children showed a strong knowledge of the range of triggers for their asthma (Rudestam et al. 2005; Dell Clark 2003; Meng & McConnell 2002; Walsh 1983), and some knew the timetable for their medicines (Koinis Mitchell 2003; Walsh 1983). Equally, children across ethnicities, ages, and in weaker and stronger studies, showed knowledge about their diabetes care, such as injections, blood testing, the timetable for these, restricted foods, the importance of exercise, and recognising and treating hypoglycaemia (Sutcliffe et al. 2004; Spezia 1991; Zahorik 1990) (Section 5.2.1 of my fieldwork study).

Studies across illnesses and ethnicities describe children taking on-going responsibility for their care. In Sutcliffe and colleagues' study children are described as carrying out their own blood tests and injections from age 4, choosing appropriate foods and refusing restricted foods, interpreting physical symptoms and explaining their illness to others (Sutcliffe et al. 2004). Zahorik describes children doing their own blood/urine tests and connecting these measures of their blood glucose levels with their own subjective, physical experiences; knowing the timetable for their injections and doing some of their injections themselves; and making efforts to restrict their intake of 'unhealthy' foods (Zahorik 1990). Children are described as taking active steps to ensure their health including vigilance about foods, monitoring exercise and ensuring their injections and tests (Zahorik 1990). Spezia describes children knowing doses, insulin types, drawing up and sometimes giving injections, monitoring glucose levels, maintaining the diet and taking exercise and making decisions in relation to their care (Spezia 1991). Likewise, in my own fieldwork, children presented themselves as active decision-makers about their care, demonstrating how they do their blood tests, and some, their injections, and describing how they take care to follow food restrictions.

Ireland recounts how children make on-going appraisals of their the severity of their asthma symptoms against personal baselines developed over time and then use problem solving techniques to control the illness (Ireland 1997). This fits with Walsh's findings that children use a range of techniques including taking medicine, resting, breathing exercises, drinking water, and relaxing to treat their asthma; and that most children initiated treatment themselves and managed symptoms without telling an adult (Walsh 1983). Koinis also found some children to do this (Koinis Mitchell 2003). Walsh found that those who treated their illness autonomously tended to use wider range of techniques that those who just told a carer when they felt symptoms (Walsh 1983). This chimes with Pradel's finding that 12 year-old children used a range of techniques such as resting, relaxing, restricting physical activity, drinking, moving away from pets, while younger children, who tend towards less autonomous care, just rest or tell their carer about their symptoms (Pradel et al. 2001).

However, it was clear from studies in the review that – unlike for most adults - partnership working alongside carers, in particular mothers, is a central aspect of most school-age children's health care (Section 5.2.1 of my fieldwork study; Dell Clark 2003; Spezia 1991; Zahorik 1990). My fieldwork findings indicate that while this was largely what children wanted and that they usually found it helpful, parental enforcement of the regimen could also be stressful (see Section 5.5.2).

Across illnesses, age groups and ethnicities, children were found mainly to understand their illness in terms of their day-to-day social experiences of interventions and physical experiences of symptoms (Dell Clark 2003; Rudestam et al. 2005; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork study Section 5.7); though some older children also showed evidence of having begun to internalise a bio-medical model of their illness (Dell Clark 2003) (my fieldwork Section 5.7.3).

Sutcliffe and colleagues' study and my own fieldwork found children's learning and taking responsibility about their illness to be gradual, taking place over time, and in cycles, so for a while children might take greater responsibility for their care, and then relinquish this for a while, perhaps to take greater responsibility again later (Sutcliffe et al. 2004) (Sections 5.7.4 and 5.7.8 in my fieldwork). Yet Pradel's methodologically weaker study found 12 year-old children to describe a more comprehensive list of triggers than 7 year-old children (Pradel et al. 2001), and when Koinis returned to interviewed children a year later, most reported feeling more confident about managing their illness (Koinis Mitchell 2003). This suggests that while learning may be cyclical, experiential understanding – and confidence – may also broadly increase across time. In addition, findings from my fieldwork study indicated that children and carers' decision-making about the sharing of health care responsibilities did not necessarily divide along lines of competence. Some children preferred carers to carry out tasks they could easily do themselves in order to save time or inconvenience (see Section 5.2.1).

6.3.6 But sometimes children may not follow their regimen because they don't understand it

When Pradel asked children about their experiences of symptoms prior to an attack, very few 12 year-old children and no 7 year-old children identified warning symptoms (Pradel et al. 2001). In both Pradel and Boyle's studies children reported the onset of an attack to be unforeseen and sudden (Boyle et al. 2004; Pradel et al. 2001). Conversely, Meng found children did have an understanding of warning signs of an impending attack, but seemed to ignore them (Meng & McConnell 2002). She suggests that this 'may be viewed as a desire to be "normal"' since ignoring symptoms allows children to continue their activities uninterrupted; but equally she later suggests that 'school-age children may not be developmentally capable of understanding' that ignoring early warning symptoms leads to worsening symptoms.

It is not clear from this data if children are making a conscious decision to ignore symptoms, or whether some younger children have yet to gain the experience necessary to know that ignoring early warning symptoms leads to worsening symptoms. If clinicians want to 'teach' this they can do this most effectively by asking children to reflect on their physical experiences of the illness.

6.3.7 Sometimes children may not follow their regimen because they don't perceive any benefits

Ireland's methodologically strong study found some children to ignore their regimen because of their inability to believe in the possibility of gaining control over their illness (Ireland 1997). Across a number of less methodologically strong studies authors reported a similar finding that children sometimes felt 'powerless' in the face of their illness (Rudestam et al. 2005; Boyle et al. al. 2004). Although this was not a finding that arose in quite the same way in the studies of children with diabetes, in both Sutcliffe and colleagues' study and my own fieldwork, one or two children living in apparently stressful circumstances were described as finding it particularly difficult to reconcile themselves to the demands of the diabetes regimen (Sutcliffe et al. 2004) (Section 5.6.3 in my fieldwork).

In both stronger and weaker studies of children with asthma, children described not taking steps to avoid triggers, because they dislike this part of the regimen, (Koinis Mitchell 2003) preferring instead, according to Rudestam and Meng's studies, to use their rescue medicine when symptoms arise (Rudestam et al. 2005; Meng & McConnell 2002). This finding did not arise in the diabetes studies, perhaps because most of the diabetes regimen is preventative, so there is less opportunity for children to favour reactive strategies over preventative ones. However, this finding in the asthma studies suggests it might be harder for children to engage with a regimen which simply maintains the status quo compared with one with immediately perceptible benefits. This may be linked to children's experiential understandings of illness described in Section 6.3.5, and implies that the value of preventative strategies is perhaps an important area for intervention by helping children reflect on their experiences of when preventative strategies are not used.

6.3.8 Sometimes children may not follow the regimen because it is more disrupting physically or psychosocially than the illness itself

In my fieldwork study some children described sometimes ignoring their regimen in order to avoid the disruption this causes them at physical and psychosocial levels – for instance, skipping an insulin injection because it would interrupt play with friends, or enjoying a pudding with their school lunch (Section 5.6.3). In Zahorik's study one child also describes 'cheating on my diet' at the school carnival (Zahorik 1990). Equally, Koinis found children with asthma to sometimes skip taking medicines when they are busy playing with friends or because of the unpleasant taste (Koinis Mitchell 2003). As described above, children also reported not taking steps to avoid triggers, because they dislike this part of the regimen, preferring instead, according to Rudestam and Meng's studies, to use their rescue medicine when symptoms arise (Rudestam et al. 2005; Meng & McConnell 2002).

6.3.9 The impact of ways of thinking about children

Unlike the authors above, Pradel suggests that children in her study did not mention avoiding triggers because of 'a lack of knowledge of appropriate avoidance'. Although she states at the start of the study that her aim is to explore children's perceptions – along with their knowledge and autonomy – it seems that in the absence of any data on children's views of why they don't avoid triggers, she has assumed the key factor to be lack of understanding. But in light of children's good knowledge of triggers - demonstrated through out the asthma studies, including by older children in Pradel's own study (Rudestam et al. 2005; Dell Clark 2003; Meng & McConnell 2002; Pradel et al. 2001; Walsh 1983) - and also the evidence described in the previous section about children's preferences, it seems that Pradel's assumption may be misjudged.

Commentators have argued that Piagetian age-stage theory frameworks for thinking about children can lead to an underestimation of children's capabilities (Alderson 1993; Sutcliffe et al. 2004). Yet Pradel is not the only author to draw on a Piagetian understanding of child development within their framework for thinking about children (Pradel et al. 2001). Koinis emphases the importance of developmental changes during 'middle childhood' (Koinis Mitchell 2003), and Walsh presents children's understandings of their illness in terms of Piagetian thinking about 'children's concepts of causality' and how an understanding of causality 'does not appear until the period of concrete operations' (Walsh 1983 p20). It is noticeable however that Pradel is the only researcher who does not, alongside a developmental psychology framework, adopt an approach that seeks to value the individual perceptions of children themselves about their own lives (Pradel et al. 2001). Koinis states that she seeks to identify the impact not only of developmental factors, but also individual, social and cultural factors on children's decisions about their asthma care (Koinis Mitchell 2003); and Walsh describes how her main aim in the work is to explore experiences of asthma in terms of 'children's definitions, perspectives about treatment and the impact of asthma on their daily lives' (Walsh 1983 p 22).

This is too small a sample to support strong claims, however it may be that sole use of a Piagetian framework, with its emphasis on children's cognitive abilities, may not only lead to underestimation of children's capacities, as Sutcliffe and colleagues argue (Sutcliffe et al. 2004), but also, because of its lack of consideration for the impact of children's social and emotional experiences, may increase the tendency for commentators' to mistake children's decision-making about their own lives for incompetence or lack of understanding.

6.4 What have children with type 1 diabetes and asthma told us about their experiences of their long-term illness and care?

6.4.1 Children's shared responsibilities and decision-making

Findings indicate that, unlike for most adults, children's day-to-day health care is a joint venture shared mostly between children and their carers, especially mothers. Children seem to make decisions in relation to their psychosocial and physical experiences of their illness and regimen as well as their understandings; though these are sometimes overruled by carers' decisions. Children seem to value their carers' input and not want sole responsibility for their health care.

6.4.2 Shifting roles and responsibilities between children and carers

The division of responsibility between adults and children does not seem to be static but – particularly in domestic settings - changes over time, with children taking more or less responsibility for their care at different times in the day, or week, and across different periods of their lives. Although older children broadly seem to take on more responsibility for self care – possibly in line with adult expectations about competence - this does not occur in a linear fashion. Division of roles and responsibilities seem to vary across different family and school settings and reflect concerns about convenience and interruption as much as competency.

6.4.3 Disruption to precious 'free' time and social identity exacerbated by social status and wider social circumstances

Children seem to have particular concerns about maintaining sameness with peers and minimising the interruption to their time caused by the illness and/or regimen. Findings indicate how children's low social status in relation to adults, combined with wider social circumstances and structures in their day-to-day lives may exacerbate these disruptions.

6.4.4 Children learning medical idioms

Though children show different degrees of familiarity with the ways illness and the body are described in modern medicine, their primary understandings seem to be based in their physical and social experiences of their illness and care. Findings suggest some clinicians may misinterpret this as a lack of competence or understanding of care.

6.4.5 Adult distrust of children's competencies

Findings indicate that where adults draw solely on models of childhood which focus on children's competencies in relation to adults they may have a tendency to mistake children's decision-making about their care for lack of understanding.

6.5 What are the key aspects of patient-centred care with school-age children?

Findings show that even very young children, or those newly diagnosed, make day-to-day decisions that affect their care. This means there is potential for clinicians to share – or acknowledge that they already share – at least some degree of decision-making with children. The proviso to this is, of course, that in UK law, children's decision-making about their health and well-being – unlike adults' - is subject to adult judgements about their best interests (Alderson 2000). Thus, ostensibly at least, and unlike with adults, there is no question of 'equal' power sharing.

Secondly, findings suggest children's decision-making is affected by their direct experiences of their illness and regimen, coloured - often, but not always - by their initial understanding of their illness and care in terms of their physical and social experiences. This means that, just as with adults (Lewin et al. 2001; Mead & Bower 2000; McWhinney 1989), a key aspect of patient-centred care is engagement with children's personal physical and psychosocial experiences of their illness/ regimen and their understandings of this.

In the next two sections I set out how what children have told us about their care may be interpreted to better understand levers and barriers to their patient-centred care. Some of this involves re-iterating what I have set out above, while other parts are based on making connections within and across findings or between findings and wider understandings of children and childhood.

6.6 What are the barriers to patient-centred care with school-age children?

6.6.1. Medical and generational hierarchies and children's desire for 'sameness'

Findings indicate both the importance to children living with long-term illness of maintaining their 'sameness' to peers and a degree of reluctance to engage directly with clinicians. It is unlikely children will find open engagement with clinicians an attractive option as long as their doing so seems absurd in the context of a wider culture where children have low social status in relation to adults and patients low status in relation to clinicians. Equally findings suggest adults also may be inhibited by these hierarchies: my fieldwork found relatively little attempt by clinicians to engage with children about their experiences of their illness and care. This chimes with findings from Tates and Meeusesen's extensive review in this area (2001).

6.6.2 Ways of thinking about children and 'blindness' to wider stressors

Findings suggest that, unsurprisingly, the frameworks we use for thinking about children have an impact, and that perhaps sole use of theories of childhood that focus on the development of children's cognitive abilities may skew attention away from consideration of the impact of children's personal experiences on their lives and choices - which include the impact of stressors related to their low social status and wider social and ethnic background. I do not mean to imply by this that attention to children's understandings of their illness and care is not important. Within the review, it was clear that children's understandings, as well as their experiences, affect their decisions about their care. However, findings from the review also suggest that theoretical frameworks which focus on children's developing competencies may work best when used alongside other models, such as those within sociology, which, conceptualising the child as a person in his or her own right, rather than a 'lesser' adult (Lee 2001), draw attention to the importance of children's personal perspectives and preferences. This finding fits with previous commentators observations that frameworks for thinking about children which focus only on children's competencies underestimate their capabilities (Alderson 1993), and that such views of children can be self-fulfilling (James and Prout 1997).

6.6.3 Children's status and shared responsibilities for health care

Findings indicate that unlike with most adults, children's health care is a joint venture between children and their carers. This means that while patient-centred care with adults may usually (though not always) involve clinician engagement simply with the 'patient', with school-age children engagement needs to be across the adult and child dyad. Children's low social status in relation to adults means that they are easily excluded from this. And engagement is further complicated by the fact that child/carer responsibilities shift between parties over time, not necessarily in a linear fashion, nor in relation to children's competencies for fulfilling health care tasks (which may exceed their choices about the about the amount of responsibility they wish to take on).

Further, with adult patients, the pursuit of patient-centred care can be guided by the potential for equal power-sharing with clinicians, even though many patients may ultimately opt for a lesser degree of decision-making along the continuum of power between clinician and patient. However, under UK law children's decision-making about their health and well-being is subject to adult decisions about their best interests (Alderson 2000). There can be no question of *equal* power-sharing between clinicians and children. This means that there is no clear continuum and potential end-point to guide negotiations. The process must rather be about exploring some less clearly defined 'middle ground', arguably extremely difficult given the medical and generational hierarchies which also impact on the clinical encounter.

6.6.4 Clinicians' misunderstanding of children's understandings of their body and illness

Chiming with previous studies (Christensen 2000; Christensen 1999; Alderson 1993), findings suggest that while some children have begun to internalise bio-medical models of their illness, most understood their illness and care in terms of their day-to-day social experiences of interventions and physical experiences of symptoms. This may be mistaken for a general lack of understanding about the illness and regimen.

6.8 What are the levers to patient-centred care with children?

Findings suggest that barriers to patient-centred care are overwhelmingly related to the ways in which we understand children and childhood. This means that there is a danger that technologies and mechanisms to ensure children have greater opportunity to set the agenda in clinical environments could become merely instruments for coercion and manipulation. If this is to be avoided we need to disseminate new ways of thinking about children and childhood and better understandings of children's experiences of their health and health care. Particularly important are models of childhood from the social studies of children which recognise the impact on children's lives of their low social status, alongside the expertise which children have about their own lives. Insights from studies of children's experiences of their illness and care – for example, on the importance of 'sameness', how children understand illness and their bodies (see Section 6.6.4 above) and about the division of responsibility for health care in families (see 6.6.3

above) – are also likely to be important. Such understandings can pave the way for the development of new, multidisciplinary ways of working with children with long-term illness.

In the early part of this thesis I described how calls for children's participation might be based on both Article 12 of the United Nations Convention on the Rights of the Child (UNCRC), which gives children the right to express their views on all matters affecting their lives; and also within wider recognition of children's expertise about their lives and the value of this to the development of effective interventions - just as the value of the views of adult stakeholders is now recognised as an important part of the evidence-base (Roberts et al. 2004; Sackett & Wennberg 1997). This second rationale makes a better 'lever' to patient-centred care at a time where, as we saw in fieldwork studies, children may be ready to waive their rights to participation under the pressure of current medical, and generational, cultural hierarchies. Under the UNCRC, children also have a right to the 'highest attainable' health care: engagement with children's personal experiences of their illness and care, and recognition of the degree to which decision-making about care is shared with children is a key aspect of achieving this.

6.9 Generalisability

While the study highlighted differences in the experiences of children living with asthma compared with children living with diabetes, the findings fit the experiences of both groups of children. As such they may also be generalisable to children with other long-term conditions.

Findings are based on studies of children across an age range of 4 -11 years with a wide range of social and ethnic backgrounds and including both boys and girls; and as such are applicable to these populations. However further studies with children from specific social or ethnic backgrounds, a smaller age-range and/or focussing on just one gender may produce more finegrained data highlighting differences in the experiences of different children across these groups. I will discuss this further in the next chapter.

6.10 Robustness

Busse and colleagues (2002) recommend that the robustness of findings from a systematic review should be demonstrated by discussion of the following items:

6.10.1 Methodology

Busse and colleagues (2002) suggest that the methodology of the synthesis used should be set out with a particular focus on its limitations and their influence on the results. I have set out a description of my methods both in Chapter 4 and, briefly, at the beginning of each section of this review findings chapter. I shall reflect on the strengths and weaknesses of the approach used in the next, and final, chapter, so, to that extent, demonstration of the robustness of the findings is a process on-going in that as well as this chapter.

6.10.2 Evidence used (quality, validity, generalisability)

Busse and colleagues (2002) recommend a discussion of the quality, validity and generalisability of the evidence drawn upon in the review. I have set out my conclusions in relation to generalisability across populations, however, I can use this opportunity to point out that each aspect of the synthesis emerging in this chapter is based on findings from at least one study judged to be methodologically strong for the purposes of this work, as I have taken pains to make clear in Section 6.4 above.

6.10.3 Discrepancies and uncertainties identified

I described in the previous section how findings are drawn from samples of children across an age range of 4 -11 years, with a wide range of social and ethnic backgrounds and including both boys and girls; and how further studies with children from specific social or ethnic backgrounds, a smaller age-range and/or focussing on just one gender may highlight differences in the experiences of different children across these groups.

I also outlined in section 6.3.6 how it is not clear from evidence in this review whether children do not understand the importance of early warning symptoms of asthma or whether they choose to ignore these because of the disruption which attending to them would cause. This is an area for future investigation.

Discrepancies between findings across studies mainly seemed to relate to the different experiences of children across illnesses or authors' differing understandings of children and their experiences. I have discussed this in the results section.

One key area of discrepancy is Pradel's suggestion about children's lack of comprehension as a motive for ignoring trigger avoidance strategies (Pradel et al. 2001): at odds with other authors' findings about personal preference as a motive. I have already discussed possible reasons for this in the main body of the findings.

6.10.4 Expected changes in technology or evidence

In the background section of the thesis (Chapter 2) I discuss anticipated changes in care for children's type 1 diabetes, particularly new technological developments. I am confident, however, that findings here do not so much relate to the specifics of intervention design, as to children's experiences of and decision-making about these.

In the next and final chapter, I will discuss the implications of findings first for health care practice, and secondly for our ways of thinking about children and childhood. I also set out my assessment of the strengths and limitations of this study. I conclude with an exploration of the extent to which engagement with children's views and choices characterises current policy guidelines for practice with children with type 1 diabetes.

Chapter 7: Conclusions

In the first part of this final chapter I discuss implications of findings for research and practice. In the second section I look at implications for our understandings of children and childhood. Next I reflect on methods used, both in fieldwork and in completing the review and synthesis. Finally, I explore the extent to which engagement with children's views and choices characterises current policy guidelines for practice with children with type 1 diabetes,

7.1 Implications for research and practice

7.1.1 Disseminating understandings from the social studies of childhood

Findings focused on the importance of disseminating new ways of thinking about children from social studies of childhood among health professionals. This raises questions about the extent to which these models are used in the education of health professionals – if at all, and whether there is also scope for dissemination amongst clinicians who are already practising. I was funded by the ESRC to carry out a short-piece of knowledge exchange work on findings from the study with six local clinicians - consultants, specialist nurses and play specialists - which revealed them to see their existing roles, lack of time, and the set up the clinic as barriers to engaging with school-age children. They seemed less aware of the low priority which they assign to engagement with children and the extent to which they sometimes conflated carer/child identities.

Priscilla Alderson arranged in-hospital seminars with clinicians to explore their concerns about the social and ethical consequences of advances in genetics (Alderson et al. 2002). A similar, participatory approach would make a good model for taking forward work in relation to clinicians' understandings of children. Alternatively, the Royal College of Paediatricians employs a Children's Participation Project Manager. It may be there is an avenue here for taking work forward.

Clinicians' engagement with children may be improved via learning about methods used in qualitative social studies with children – see section 3.13 for an overview of these. Christensen's recommendations about observing children's styles of communication and reflecting these in one's own approaches may be valuable (Christensen 2004). Other useful starting points may include ideas about centring engagement around certain kinds of activities routinely practiced in children's day-to-day lives (Curtis et al 2004b; Lancaster 2003; Punch et al 2002; Christensen 2001; Bradding 1999; Backett 1991) or tools that have proved useful for hearing children's views in other settings (Children's Society 2008).

7.1.2 Engaging with children's experiential understandings and ways of learning

Findings indicated how children sometimes did not follow their regimen, not because of its personal costs, but because of their lack of understanding of the intervention or lack of perception of its benefits (particularly in the case of preventative measures). This chimes with previous research that has found children to primarily understand their illness and care in terms of their physical and social experiences and perceptions (Christensen 2000; Christensen 1999; Alderson 1993). The importance of aspects of the regimen with immediately perceptible physical outcomes may be more readily perceptible to children. Where care involves preventative medicines or measures with less readily perceptible physical outcomes, children may need support from adults – clinicians or carers - to reflect on the role of preventative measures, in terms of children's own experiences of times when they have not followed these, and the physical experiences that have accompanied these.

Findings from the review also suggest that accessible and practical educational support needs to be available on an on-going basis, since children's learning about their illness and care takes place cyclically, over time. Further, findings from my fieldwork indicate that children's take up of responsibility for different parts of their regimen may not be linear over time, and may not link directly with understanding or capability, but with other factors, such as having enough time, or not feeling tired.

These findings not only have relevance for training clinicians to engage with school-age children primarily in terms of what they say they 'do' and 'feel' day-to-day in relation to their illness, and to use these understandings as the basis for beginning to introduce bio-medical models of the illness, but they also have important implications for the development of interventions to support children's management of their care (Barlow & Ellard 2004; Bradley & Gamsu 1995).

Further findings that some children lack a belief in their own ability to control their illness suggest the importance that children's education about their illness and care focus on practical problem-solving techniques that will deliver easily perceptible outcomes. Again, children may benefit from supportive adults helping them reflect on the impact of the decision-making about their care in terms of their personal physical experiences, or from measures to mitigate the personal cost of the illness or regimen. Although many children described preferring clinicians not to directly engage with them in their out-patient clinic appointments, in my own fieldwork I felt that this practice undermined children's perceptions of their own importance in their illness care, and may have even endorsed the beliefs of those who doubt their ability to control the illness themselves. This may be an area for further research.

7.1.3 Supporting families to cope with the impact of poverty and exclusion

In the introduction to the thesis I described how despite the fact that social and economic exclusion remains a defining experience for many people from minority ethnic backgrounds (Karlsen & Nazroo 2002; Spencer 1996), it is ethnic, religious, and linguistic differences that are the central focus for best health care practice in multi-cultural settings (Australian Government & National Health and Medical Research Council 2005; Helman 2005; Helman 2001). However, just as previous studies have found that it is harder for those experiencing stress and disadvantage to manage their illness (Healthcare Commission et al. 2005; Anders et al. 2002; Amer 1999; Bradley & Gamsu 1995), so findings from the review made clear how the personal cost of illness and care for children in disadvantaged and multi-cultural populations can be exacerbated by socio-economic stress, arising from, for example, poor housing, social isolation and low income.

Multi-disciplinary working by specialist nurses across education, housing and social care may be critical in helping children and families cope, especially as more complex interventions - such as the insulin pump and/or dose-adjusted approaches to eating - become more widely available. It might be hoped that the development of Children's Trusts may facilitate the work of specialist nurses, though findings from the review of Pathfinder Trusts published in March 2007 suggest that barriers to multi-agency working at operational levels are still strong (University of East Anglia & National Children's Bureau 2007). In diabetes clinics, shortages of appropriately trained staff is a problem (Jefferson et al. 2003). This indicates the need for improved planning and resourcing of staff training and recruitment – and the vital importance, at a macro-level, of on-going attempts to address child poverty (Joseph Rowntree Foundation 2006).

This is not to say that what I observed and heard from children and parents in my own study, or read in the findings of others, did not flag up important issues relating to cultural or linguistic difference. The most striking of these was, in my own fieldwork, the very great importance of flexibility in the provision of interpreting services. Carers' needs for these services seem to change over time and access needs to be available on an on-going basis - including to those who may have previously decided against using an interpreter. Further, perhaps because of conflict in home countries, some families seemed to have difficulties working with particular interpreters. It is important that, where possible, families be offered a choice of individuals with whom to work.

Secondly, Boyle (Boyle et al. 2004) in her study of African-American school-children with asthma, expressed concern that correct diagnosis might be jeopardised by the children's use of very general or culturally specific language about their illness. Clinicians' capacity for cultural self-assessment and awareness of the dynamics that occur when cultures interact is of course critical (Australian Government & National Health and Medical Research Council 2005). Yet, findings from my own fieldwork about how participants' lives did not conform to cultural stereotypes about community and family support also indicate the importance, alongside this, of using information on people from minority ethnic backgrounds as a context for interaction, instead of a tool to assume behaviours and beliefs (Australian Government & National Health and Medical Research Council 2005). The identities of children in my fieldwork study seem as much influenced by their being children growing up in East London at the beginning of the 21st century, as by their particular ethnic background. I have described in Section 5.1 how their ideas about their ethnicity seemed to differ from those of their parents; it is also interesting that the code names they chose for themselves are drawn without exception from minority world pop culture. Observations by the sociologist Sharon Stephens on children's multiple cultural identities in a globalised world seem particularly relevant here (Stephens 1995).

7.1.4 Concordance

The term 'concordance' relates to the idea of harmony between clinician and patient agendas (Sanz 2003) - most likely to be achieved when the personal 'cost' of the intervention to the patient does not outweigh the personal 'cost' of the illness. This is only likely to be achieved if children are involved in every stage of the development of interventions and subsequent discussions of treatment, since adult assumptions about what they may find helpful may be misleading. For example, children with diabetes in the review disliked the unremitting regimen of 'pricks' for blood tests and insulin injections – so the alternatives to insulin injections currently under development, such as inhaled insulin, may be valued. Yet, children also wanted interventions to be quick and inconspicuous, so if new ways of delivering insulin are to be successful they must also fulfil these criteria. Ruben, in my fieldwork study, said he would prefer injections over an inhaler since, unlike an inhaler, he can leave his injecting equipment at home when he goes out to play. Similarly, children found dietary restrictions relentless and intrusive, but also valued interventions that caused minimum disruption to their day-to-day activities. Training courses for teenagers who wish to learn dose-adjustment approaches to care are currently under development (DAFNE Study Group 2002), and such approaches may also prove popular with some children. However, the extra time and effort involved in calculating insulin doses in relation to food intake may, for some, outweigh the advantages of greater freedom around food choice.

Findings from my own fieldwork also suggest that concordance might be bolstered via engagement with children's views:

- Children's fears about routine clinic treatment, such as the annual blood test, may be underpinned by previous traumatic experiences of emergency care. There may be opportunities for explaining how routine treatments will differ from experiences of emergency care in order to help children feel less afraid.

- Exploration of children's fears about long-term consequences of their illness: though children are routinely exposed to information about these, they may be reluctant to raise questions because of their understanding of adult disquiet around child morbidity and mortality. Open discussion of children's knowledge and concerns in this area is important to prevent the sharing of inaccurate or misleading ideas, which left unexplored, could cause even greater psychological distress.

- Children demonstrated a variety of identities which allowed them to accommodate the imperatives of the regimen without compromising their sense of being 'normal'. These varied for different children. Clinicians' explorations of children's day-to-day experiences of living with their illness may support children in the development of these. Ensuring clinic timetables do not routinely hinder children's involvement in relevant activities is also vital.

Findings also suggest the potential impact of different kinds of support on children's experiences of the balance of their personal 'costs' of illness and regimen, and I discuss these further below.

a) Support/interventions to mitigate the personal cost of interventions and illness

Children across review studies who took part in asthma or diabetes camps reported enjoying being with others who shared their illness and how this lessened, at least temporarily, some of the psychosocial costs of the illness (Dell Clark 2003; Spezia 1991; Zahorik 1990; Walsh 1983). These may have potential in mitigating the personal cost of interventions and illness, though all review studies in this area were carried out in North America, so further investigation in UK settings may be warranted.

Dell Clark, a play specialist, described in her study how children drew on stories, humour, play, and ritual to help them cope with their illness and treatment; for example, giving an imaginary Pink Panther character insulin injections, taking a favourite Power Ranger toy along to the clinic, enjoying a fantasy board game about eating sweets, and developing the ritual of hitting the parent after the injection, or singing, being hugged, holding their breath or breathing slowly and evenly during the injection (Dell Clark 2003). She concluded that it is important that adults support children's ways of coping through play, story, ritual and humour. The implications of this are not only the provision of play services for children with long-term illness, but also perhaps support for parents to help children develop play. Current evidence suggests that psychoanalytic psychotherapy may be useful for hard to control diabetes, and family systemic therapy for asthma (Wolpert et al. 2006). Exploration of the state of the evidence-base relating to play work may also be useful.

b) Systems to tackle structures which exacerbate the personal cost of illness and care

I have already described in the previous section the importance of the role of the specialist nurse in supporting families to cope with the impact of poverty and exclusion. Findings from the review also made clear how systems in schools often exacerbated children's difficulties in looking after their illness or exacerbated their sense of difference arising from their illness. Children in Nabors' study of diabetes management in schools in particular called for greater peer support, both practical and emotional, and improved teacher knowledge, practical support and systems for looking after their diabetes (Nabors et al. 2003). At the end of her study, Sutcliffe and colleagues argue that the current climate in schools, with a strong focus on pupil achievement, means that staff have little time to plan to meet the diverse needs of children, and it this that can lead to an inflexible and unsupportive environment (Sutcliffe et al. 2004). Certainly the role of the specialist nurse in working with schools to try to ensure and improve systems for children is vital.

7.1.5 'Child-and-family-centred' care

Finally, in my fieldwork, children clearly emphasised the role of their parents or carers in looking after their illness alongside themselves. It may be that previous work has needed to emphasise children's role outside of carers' input in order to make the case for children's agency (Prout 2006). In this study, as I have described, children did seem to see themselves as key players in their health care, as has been found before (Christensen 1998; Mayall 1994a; Alderson 1993). However children were also very clear about the extent to which this is partnership working *alongside* parents (Section 6.3.5). This means that far from replacing the model of 'family-centred' care for a model of 'child-centred' care, we rather need to be focussing on finding a model for family-centred care that does not exclude the child: (overlooking the clumsiness), a 'child-and-family-centred' model (Shields 2006; Franck 2004).

7.2 Thinking about children

7.2.1 The impact of generational inequality on experiences of long-term illness and care

Children's experiences of their illness and care stand out as particularly different from adults' accounts not only in terms of their being doubly disempowered in relation to clinicians, both as patients, and as children, but also in terms of the nature of their concern about impact on social identity. Much of the focus in adult accounts is on 'biographical disruption' and processes of 'legitimising' this (Bury 1991). By contrast this review found children's concerns to centre around maintaining 'sameness' to peers. There are two possible reasons for this. The first relates to children's position on the lifecourse: continuity in self-identity may be less important for those early on in the life course than for those further along. Alternatively, or in addition, it may relate to children's social status. In findings from her extensive fieldwork with children in primary schools, Mayall (2002) suggests that children's low generational status leads them to make 'common cause' with peers: alliances with peers are important in the face of generational inequality. This would explain why children with long-term illness seem to feel threats to their 'sameness' so keenly and why this may be a higher priority for them than repair to pre-illness identity.

Findings from the review indicate that some children experience adult actions in relation to their illness at home and school as primarily supportive, while for others this is oppressive and inhibiting. There is scope for future work to explore how children's experiences of generational inequality vary in relation to other structural factors, and how this impacts on their experiences of managing illness and care. For example, Clare Williams' study (2002) with teenagers with type 1 diabetes found maintaining 'sameness' or 'normality' in relation to peers to be a greater concern for boys than girls. Equally, in my fieldwork there was some indication that boys may have found it harder to accommodate an identity that involved expertise about their illness and care, and therefore a degree of difference from peers – though the sample size was not large enough to explore this in any detail.

Children's generational status may also account for their other major concern in relation to their care: interruption in precious play or 'free' time. Commentators have observed increasing adult restriction of children's access to this valued resource (Roberts, 2000). It is not surprising therefore that further disruption from health care regimens should be so resented. Mayall's fieldwork (2002) with primary school children found those who attend Madressah schools after school to be particularly short of 'free' time. It may be that interruption arising from health care may be particularly keenly felt by these children.

7.2.2 Children as 'becomings'

I want to turn now to consider the impact of children's emotional 'pricelessness' to adults, the rise of which, in the USA, has been charted in relation to their falling economic value, by the sociologist Viviana Zelizer (1981). In turn, in her study of children with leukaemia, Bluebond-Langer (1978) found children's high emotional value to be related to adults' perceptions of children as still in the process of 'becoming' or 'under development' which made it difficult for parents to countenance the idea of their physical vulnerability, their mortality. The idea that they might not 'achieve adulthood' was untenable. I had a similar experience in the course of my fieldwork. In my previous studies with 'healthy' children I have found it relatively easy to reject what Christensen describes as the 'traditional' adult role of 'protecting or looking after' children (Christensen 2004, p 174). However, as this study progressed, I noticed that this was not the case here. I found myself internally willing children to give the 'right' answer to questions about how they are managing their illness, and wanting to explain aspects of their regimen to them that they appeared to misunderstand.

In light of this it seems that it is not only a lack of trust in children's capacities but also a view of them as vulnerable 'adults-in-the-making' that contributes to children's emotional value to adults, and hence the adult impetus to control children's decision-making about their lives, in particular health care. For all that we can make the case for the political importance of seeing children as people in their own right, it seems unlikely that the idea of children as in preparation for adulthood will lose much ground given the extent to which it shapes both adult and children's ideas of childhood globally (Stephens 1995). Rather perhaps it is recognition of the growing extent to which we, as adults now, are in a state of 'becoming' (Prout 2005) that may loosen this stranglehold and create space for children's greater autonomy. This leads to the final part of my discussion: children as a minority group.

7.2.3 Children as a minority group

Reflecting on her extensive fieldwork with children in primary schools, and findings about extent to which children live their lives subordinated to adults, Berry Mayall ascribes children the status of a minority group (Mayall 2002). Findings from this review – and indeed from Mayall's own work – suggest the need for a more nuanced view. Specifically, children in this review made clear that much of adult supervision of their care, particularly in the home, is highly valued. They did not want to take sole responsibility for their care. This chimes with findings from Mayall's fieldwork (2002) that children see childhood as a privileged time where, in exchange for varying degrees of subordination, they can enjoy freedom from the responsibilities of adult life. This contrasts with the way that many others who are ascribed minority status on the basis of their gender or ethnicity have fought, and continue to fight for higher status and the responsibilities that accompany this. Children in the UK do not seem to be engaging in this kind of a conflict. In fact, in his commentary on the state of adult-child power-sharing in public arenas in the UK, Nigel Thomas comments on the extraordinary degree to which these are conflict-free (Thomas 2007).

7.3 Reflections on methods

7.3.1 Fieldwork strengths

a) Written and face-to-face invitations

The table below shows pathways to participation for each of the children and their families who took part: about half responding to written invitations and half to face-to-face meetings in the clinic. This seems to indicate that, as was suggested in the methods section, in order for research invitations to be accessible in these populations, it is helpful if they can be offered verbally, face-to-face, as well as in clinic.

	Tower Hamlets clinic	Newham clinic
Participants whose parents responded to written invitation to all 140 children in sample frame	3	5 (including 2 siblings)
Participants approached in the clinic who wanted more time to consider (I rang them later)	1	2
Participants approached in the clinic who responded on the spot	1	5 (including 2 siblings)

Table 7.1 Children and carers' decisions about involvement

b) Flexible, child-led methods

Because of their open-ended nature, creative or activity based methods have come to be described as 'participatory': children can influence the content and the pace of interaction, and there tends to be fewer "right" answers, which helps to offset the power imbalance between researcher and researched (Punch 2002; Christensen & James 2001; O'Kane 2000). Commentators suggest that the outputs from such approaches should not be analysed in isolation, but rather used as a stimulus for talk and analysed alongside findings from discussion (Harden et al. 2000; O'Kane 2000).

The flexible, child-led methods I used to explore children's views proved especially useful in that I did not need to make any particular adaptations when working with one boy whose carer subsequently described as having special needs. It was simply noticeable that the pace of the work was much slower, less intense and more play-based, so that I spent more than twice the amount of time visiting with this child than I did, on average, with other children. The strength of not having 'special' methods for 'special' children is that it avoids the assumptions about individual children that may accompany these. Picture-based techniques for working with older children whose verbal communication is limited may be useful across populations of children of different ages both with and without verbal communication difficulties, since in one population the symbols could function as a form of communication and in another as a stimulus for discussion.

c) Information booklets using simple language and pictures

In preparing the A5 information booklets for children about the study, my hope was that these to some extent seemed similar to story books that children may have read with - or had read to them by - adults, and that as such, they would find them more useful than conventional research information materials. I had hoped that while younger children and parents used the leaflets together, they would be equally appealing, in style and imagery, to older children who would be able to read them themselves, and I was happy to see children doing this in the clinics when I handed them out. Yet, the weakness of this approach is that it assumes parental or carer literacy, and initially this seemed an insurmountable difficulty. However, my experience as I did the study was that parental literacy did not seem to fall into absolute categories of literate, or not, rather that parents were more or less confident of reading at different levels in different languages, specifically, some feeling more confident reading simple English than anything written in the language spoken in the home day-to-day. To this end, provision of colourful, attractively laid out information in simple language was useful for children and carers alike; though of course this does not preclude the possibility that some carers refused participation because they were unable to read leaflets in any language, and also felt uncomfortable discussing the study with me face-to-face.

d) Meeting children at home

I had originally intended, on home visits, to ask children and carers for private space to meet with children alone. However, after my first three pilot visits, I decided this was impractical, since most families' homes had only one comfortable seating area, and to request sole use of this – or alternatively, request use of the child's bedroom as a meeting place – felt demanding and disruptive. Lil'Bratz' mother was the only carer who showed me directly into her daughter's bedroom, where we stayed for the duration of both my visits. All other visits I spent mainly in the family living room, though several children also took me into their bedrooms to show me toys, games or pets, and some mothers took me through to the kitchen for a cup of tea and in one case a meal. Some carers stayed with their child for most of my visit (6), only absent for short periods to get refreshments from the kitchen. However, most others spent some time sitting and observing, and some time out in the kitchen preparing food, or busy elsewhere with other household chores. Two mothers were almost entirely absent, cooking or cleaning in other rooms for the duration of my visit. While it could be argued that children are less likely to give 'private' accounts (Cornwell 1984) of their experiences when carers are around, I found that I learned much about children's experiences from their interaction with others in this public space: siblings and their visitors came to see what was happening, and sometimes joined in games, drawing and discussions; carers sometimes helped children demonstrate their diabetes care equipment, or offered prompts about events they felt to be relevant (Sutcliffe et al. 2004) – to which children sometimes responded in agreement or hotly disputed. Carrying out visits in this way seemed to offer greater opportunity for observation of the 'naturally occurring situations' (Lofland & Lofland 1995) so valued by ethnographers, than would have been the case had I pressed for entirely private space to meet with participants.

7.3.1 Fieldwork: areas in need of development

a) Ensuring children's control over their participation

Where families returned reply-slips I could have little idea about the degree of children's involvement in decision-making about expressing interest in the study. Although I designed reply-slips to be filled out by children ("My name is....; My parent's name is...), all looked as though they had been completed by an adult. For this reason, when I met with children and families subsequently, I was careful to apply the strategies described in the fieldwork methods chapter to ensure, as much as possible, that the decision to participate was taken by the child rather than the adult. However, in some situations where I introduced the study in person, I could clearly see that it was solely the carer who responded no, without recourse to the child's opinion. When this happened, I did not feel it would be appropriate to make a point of asking children's views, but when carers offered to participate without asking their child, I also turned separately to the child and asked them for their opinion. These experiences show how, ironically, it can even be hard to ensure children get a chance to decide about their participation in a study which rests on an assumption of the importance of their having a say.

b) Double-checking fit within the sample-frame

Although letters of invitation were only sent to children with insulin-dependent diabetes, the sample did eventually include one girl - who chose the code name Little Miss Perfect - who was not insulin-dependent, though she followed the same dietary guidelines as her insulin-dependent brothers. In her family the letter of invitation to the study was sent to her younger brother, Trunks. However it was Little Miss Perfect who came to meet me with her mother to find out more about the work, and I did not realise she was not insulin dependent until after she had joined the study. She was so clearly enjoying participation that I felt it would have been unkind to ask her to drop out; and her contributions were similar enough to those of other children to suggest that her inclusion did not compromise the internal validity of the study, nor the potential for judging its generalisability to other contexts. However to avoid this in the future it would be important to double-check inclusion criteria with children at the point of inclusion.

c) Central Office of Research Ethics Committee's on-line application process

This application was the first I had made using the new Central Office of Research Ethics Committee's (COREC) on-line, electronic form, with which

I experienced considerable problems around access, navigation and transparency. I understood from telephone operators at the help centre, at that time, that some of these were in the process of being addressed. I also spent considerable time eliciting and co-ordinating paperwork – for example, letters of indemnity, Data Protection forms, honorary contracts and peer reviews - across the three main bodies involved – the University, Barts and the London Trust, and Newham Primary Care Trust (PCT). I found building strong, positive relationships with the administrative staff across these organisations invaluable in this.

d) Guarantees of anonymity

In the course of the study, I realised that the guarantee of anonymity stated in the information leaflets was not necessarily sustainable, since although children's names might be changed, descriptions of the circumstances of their lives in the study report might make them identifiable to some people, for example, clinic staff; and this was particularly the case for the two children with insulin pumps because of the small number of children with pumps in the sample frame. In this situation, I explained to the children that they probably would be identifiable to staff, though they seemed unworried by this.

e) Timing and venues for visits with children

Three mothers requested I meet them and their child for the second time at the clinic when I carried out the observation of their appointment with the consultant. Because of the infrequency of children's attendance at the clinic, summers spent abroad, and illness, I did not meet up with these children until 6 – 12 months after my initial visit to their homes. I felt that the quality of these meetings also suffered by having to be fitted around the schedule of the clinic, rather than following children's preferences for engagement. Further, only on one occasion was I able to find a private room for us to talk, and this unfortunately only available for 20 minutes. While I made some useful observations in waiting rooms (see below) and also found our shared waiting time a useful time for getting to know children better, it was difficult to sustain engagement in busy waiting rooms – especially as, on one of these occasions, the fire alarm went off and we had to finish the 'who decides?' game outside, perched on the edge of a concrete planter. Although flexibility in fitting in with families' preferences is important, in light of these experiences, I feel data collection would have been strengthened by requesting a least two visits in the home.

f) Use of disposable cameras

When I gave them the camera, most children were very enthusiastic about the idea of taking pictures of the important things in their lives. However, despite reminders from me, only eight families returned the camera in time for me to get the film developed before our final meeting. Those children with whom I discussed their photographs seemed to very much enjoy this process, excitedly pointing out different people and places, and, in several instances, moving on to show me other pictures of their lives. To this extent the tool worked successfully as a stimulus for finding out more about children's day-to-day lives. However, in two instances, because of the delay between my home visit and a second meeting at the clinic, I sent the developed photographs back to children ahead of time, and in one case this subsequently proved problematic, since, unsurprisingly, the child forgot to bring the photographs to our meeting at the clinic. Five others lost their cameras and did not return them at all. There was a gap of at least four months between my first and second meetings with three of these children, so on reflection, I realise I should have contacted families about returning the camera about a month after the first visit, rather than leaving reminders until a month before my final visit. Three other children returned their cameras to me, but not in time for our final meeting. In several instances, children told me that they had wanted to keep the camera to record some future event that was important to them, such as a holiday. In order to try to overcome this problem with several subsequent participants, I sent the camera ahead of my first visit. In these cases, looking through pictures together at our first meeting acted as an effective 'icebreaker'. However, the missed opportunity to remind children in person about using the flash indoors meant that many of these photographs did not come out, and so I abandoned this approach after several pilots.

In conclusion, use of disposable cameras was a valuable tool in finding out about children's day-to-day lives. However ensuring return of the cameras in time for discussion of the photographs proved a time-consuming, and not easily achievable, task. If I repeated this exercise, I would give children and families earlier reminders about returning cameras, and accept that, even then, some children may have private agendas that render them unwilling to return cameras within the timescale of the project.

g) Research alongside interpreters

Several complications arose in carrying out this research using interpreting services. The first of these was that in one case, despite briefing prior to the study, the interpreter did not always adhere to her role of simply interpreting for the participant, sometimes engaging in extensive conversations with her, of which she was only able to offer me a précis at the end. Further, it became clear that she sometimes switched to an advocacy role, where she conflated her client's views with her own concerns about health and diabetes. I was aware both of how this excluded me from properly understanding the participant's concerns, and also how on-going reminders from me on the importance of precise interpreting compromised the flow and spontaneity of interaction.

Another issue that arose was that while several carers whose first language was not English chose not to have an interpreter, in some cases I began to have concerns that they did not always understand what I said, and that at other times I did not fully understand what they said. I found this a very difficult situation to manage. I felt it would have been insulting for me to have suggested that we did need an interpreter, but I also felt that our interaction suffered because of my inability to speak their first language.

Reflecting on these experiences, I concluded that the problems encountered in this study were not significantly detrimental to the work because of its focus on the meanings and experiences of children, who all spoke English. However, these experiences highlighted for me the problems with this model of involving interpreters in qualitative research and seemed to indicate the value of alternative models which recommend much closer, collaborative work with interpreters (Larkin et al. 2007). Further, I reflected that in some settings, where participants' lives are likely to be particularly complicated and stressful, employment of bi-lingual researchers might be a priority.

h) Feedback on the research process

At the end of my last visit with children in my fieldwork I asked them for their opinion of what it had been like taking part in the project and what they would have done differently. On reflection I felt that this second question was not an easy one for children to answer on the spot, since only one child formulated a criticism of the approach: that many of the questions I put to her about her illness would have been better answered by her father - 'he knows all the information' (see Chapter 5 Fieldwork findings). In light of this, it seems the best way of ensuring participants influence both the process and content (Alderson & Morrow 2004) of a study such as this seems to be primarily children's involvement in the development of the work – for instance priorities for research, design of instruments and so on – and the employment of a range of flexible and open-ended methods wherein the researcher follows the pace and cues of participants.

i) Sample size

In the methods section (Chapter 5) I described how I analysed fieldwork data by using the constant comparative methods to identify themes and sub-themes and then, within each sub-theme, made comparisons across the experiences of different children, looking for patterns in relation to their age, gender and ethnicity (Ritchie & Spencer 1994). In the subsequent write-up of findings I described a number of patterns which emerged in relation to age but no particular patterns by ethnicity or gender. This was because the numbers of children from each ethnic background or gender reporting each sub-theme were too small to stand as a basis for making generalisations in relation to these characteristics. For example, participants who gave examples of learning by watching included one Somali girl, one Somali boy, two White UK girls, one White UK boy and one Arabic girl. Studies which seek to explore a range of characteristics such as these, need a much larger sample size. Collating findings from a range of smaller, existing studies into one larger review, as demonstrated in this work, may be a way forward with this.

j) Impact of order of review and fieldwork analysis

Finally, reflecting on my fieldwork findings, it was clear to me that my choice of themes was not only affected by my having read accounts of adult experiences of long-term illness, but also by having already started reading the papers that were to make up the review, and further by having worked as a co-researcher on Sutcliffe's study (Sutcliffe et al. 2004). It seemed helpful to me that I should have exposure to a range of thinking on pertinent issues before developing the themes for my analysis of fieldwork. This meant that my attention was already alerted to particular aspects of children's experiences, such as the relentlessness of the regimen of needles for children with diabetes, or the impact of painful emergency care on subsequent expectations of care, the importance of the desire to be normal, and the difficulties which care in school settings created. Qualitative data analysis or indeed synthesis is a context-specific process: different reviewers produce different lists of themes on the same data; and the same reviewer does not produce the same set of themes on the same data set at two different points in time (Popay et al. 2006). What can be predictable or transparent in the interests of ensuring methodological rigour, however, is the account of how the process was carried out. Aware of this, I was careful to point out in the fieldwork methods section that my exposure to the ideas of studies in the review pre-dated my analysis of my own fieldwork data - and there is no doubt this impacted on the shape of findings.

7.3.3 Qualitative review and synthesis

On concluding my synthesis of review study data I was pleased that, having been dissatisfied with the value of my first, aggregative thematic analysis (see Appendix 13), following more closely the methods outlined in Narrative Synthesis (NS) (Popay et al. 2006) I was able to produce a synthesis that successfully integrated aspects of the review studies and answered my research questions. Approaches recommended in these guidelines facilitated judgement on:

- how findings from studies more or less methodologically strong for the purposes of the work might be weighed up against one another and findings from less robust studies reported in the context of needing further exploration

- how findings from studies of different populations might relate to one another and the implications of these for overall findings from the synthesis

- and how the individual views and perspectives of authors may have affected their findings.

I was particularly happy with the way that I devised of setting out my judgements about these within a narrative about findings under each theme heading, since, while Popay and colleagues provided guidance on a range of tools for doing the synthesis, they did not describe ways of clearly setting out how these were used in relation to one another, and this was something with which I initially struggled (Popay et al. 2006).

In the early part of the thesis I reported that I would reflect in the conclusions on my decision to extract data only from the child, rather than data from carers or parents also. My reasoning for this has been influenced by commentators' suggestions about the importance of ensuring children, not their carers, are at the centre of social studies of childhood (Qvortrup 1994), and warnings that children's perspectives can be obscured in studies of the child in the family context (Mayall 1996). Reflecting on this decision, having completed the study, I am still happy with it, since during the course of the work I came across a number of studies that purported to include children's views but in fact concentrated on adults' perspectives (Buford 2001; Nicholson 2001; Ambrose 1997; Horner 1992). This confirms my view that while studies of carers' perspectives are important for informing decision-making, it is better that children and adults' views be collected as part of two separate processes in order to ensure children's views are not obscured.

Finally, I was pleased with the way in which the review functioned not just as a synthesis of findings, but also to reveal something of the impact of authors' ways of seeing children on their findings. This more 'literary' examination of secondary data was also used by Thorne and Paterson in their review of how researchers have represented long-term illness among adults over time (Thorne and Paterson 1998).

However, I also had several concerns about the processes of synthesising data for the qualitative review:

a) What constitutes the 'findings' in Narrative Synthesis (NS)?

I was concerned by the fact that findings generated within the NS synthesis did not include all findings from studies relevant to the research questions – for example, the poor understanding of paediatric type 1 diabetes among general and ward staff (Sutcliffe et al. 2004). This raises the question of which part of NS is actually 'the findings'. In retrospect, the synthesis which emerges may prove useful for understanding processes underpinning research questions, but it may be that textual summaries of study findings, which provide more detailed data on the individual issues raised in each, are as relevant for answering research questions.

In light of this, it seems NS encompasses two processes: the first, a distillation of findings across studies that relate to one another into an explanation of what is observed; and the second, summarising findings not only as a means to an end, but also comprising findings in their own right.

b) NS as a team-based process

Both in my aggregative, and in the second, more interpretive synthesis, as I carried out line-by-line analysis of study findings to identify themes, I was aware that the extent to which themes are either aggregative – summarising findings – or interpretive – reinterpreting data into new concepts – is more often a question of degree than absolute difference, since any summary of data, however close to the original, comprises some reinterpretation of authors' data. It is interesting that findings from the aggregative synthesis (Appendix 13), while they do not centre around one particular theory or model of children's decision-making in the way that the findings from the Narrative Synthesis did, certainly had many similarities and overlaps with the NS findings.

All of this illustrates the extent to which synthesising qualitative data is a 'messy' task, comprising an infinite series of judgement calls with no 'right' answers. In their guidance, Popay and colleagues are open about how different researchers produced different understandings of data - as did the same researchers working at different times. Yet, at the same time, in the interests of robustness, one needs to be ready to explain or defend this context-specific decision-making. This is an irresolvable tension, and one I found very difficult to bear as a researcher working alone. I would have warmly welcomed the opportunity to discuss data categorisation and the development of themes with a fellow researcher, not just to make the processes of my decision-making more explicit to myself but also to share some of the responsibility for these provisional judgements with someone else. It is no coincidence that several instruments for checking the quality of qualitative papers cite the importance of independent raters in qualitative data analysis (Thomas et al. 2003). My feeling is that NS is a process best suited to team-working.

c) *Use of the NS guidance for more or less interpretative syntheses*

The tools I used in my first, aggregative synthesis were largely drawn from Popay and colleagues' guidance, the same tools I used in my second, more interpretative synthesis. The degree of aggregation or interpretation in the synthesis therefore seems to lie more in researchers' individual decisions about the development of themes, than in the tools themselves.

d) Impact of including one's own studies within a review

It will be very clear to anyone reading this final chapter, as it was to me, that findings from studies in which I was directly involved – the fieldwork described in this thesis and also Sutcliffe and colleagues' study (Section 6.1) – took greater prominence than findings from other studies in this Conclusions chapter. Because of one's very close relationship with the data in studies on which one has worked directly, I think this is to large degree unavoidable. I think it would only be problematic if it had led me to exclude pertinent findings from other studies, which it has not. Interestingly, I do not think this is a pattern that has emerged in the synthesis of studies described in Chapter 6. It seems a credit to the tools of Narrative Synthesis, and also to my own efforts to reflect on my use of these, that this is the case.

An alternative strategy might have been to exclude my own work from the review. However as I have already explained, my own study was the only one with a sample of children with diabetes from predominately minority ethnic backgrounds. Without this study, I would not have been able to gauge whether or not the synthesis that emerged in relation to children with asthma with minority backgrounds also applied to children with diabetes – though I also acknowledge the fact that this will need testing in relation to specific minority groups as well as heterogeneous populations.

7.4 Children's views in current guidelines for practice

As part of this study, I was interested to investigate the extent to which engagement with children's views and choices does or does not characterise current guidelines for practice with children. Taking paediatric type 1 diabetes as an example, I reviewed the studies underpinning guidelines, looking for qualitative work engaging with children's views and perspectives.

7.4.1 NICE guidelines for managing paediatric type 1 (National Collaborating Centre for Women's and Children's Health 2004a)

The National Centre for Health and Clinical Excellence (NICE) states that it is committed to producing guidance for the NHS that reflects the views and concerns of patients (National Institute for Health and Clinical Excellence website). Yet in the evidence tables (National Collaborating Centre for Women's and Children's Health 2004b) of studies cited as informing the guidelines for managing paediatric type 1 diabetes (National Collaborating Centre for Women's and Children's Health 2004a) only three out of over 600 are described as including an open-ended instrument to explore patient perspectives (Hanna & Guthrie 2001; Nicholson 2001; Hatton et al. 1995;). In two children were not included at all and, in the third, it is not clear from the full study report whether, when the author describes collecting data from "families", he or she means that children were asked for their opinions. There are no direct quotations from children sitting alongside quotations from adult participants (Nicholson 2001). Perhaps it was to address this imbalance that authors of the guidelines report that a consultation day was held with 21 diabetic teenagers and their families in order to gather their opinions on issues raised in the guidelines (Datta & Olle 2002) – though the approach to recruiting young people, mainly through Diabetes UK, meant that those taking part were likely to be more informed about diabetes and diabetes services than the general population of young people with diabetes in the UK. The views of children were not sought.

A final point about the NICE guidelines for paediatric type 1 diabetes is a corresponding lack of quantitative evidence from children. Burt and colleagues (Burt et al. 2004) found only a minority of the recommendations to be based on randomised-controlled trials (RCTs) with children. They warn that compared with the evidence available for adults, there is a lack of good quality RCTs and systematic reviews on managing type 1 diabetes in children. At the moment, this gap in the evidence is made up by drawing on what they described as low quality studies, consensus from health professionals and data extrapolated from adult studies.

7.4.2 Paediatric sections of the Diabetes NSF (Section 3 and Section 5)

> All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process. Standard 3 (Department of Health 2001a)

> All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.
> Standard 5 (Department of Health 2001a)

Detailed summaries of the studies that underpin recommendations in the Diabetes NSF are not available in the public domain. However authors of the NSF report that the standards are informed by the views and experiences of people with diabetes. A qualitative study of the views of users of diabetes services was commissioned by the Department of Health (Hiscock et al. 2001) specifically to inform the development of the Diabetes NSF. No children or teenagers took part in this.

It seems that, despite the rhetoric, at least in the field of paediatric type 1 diabetes, the government's call for patient-centred working with children does not for the moment, extend to their own practice in the compilation of guidelines. This may be an example of what I warned about earlier in the chapter: that without shifts in ways of thinking about children, calls to participation are likely to be empty at best, and coercive or manipulative at worst.

7.5 Summary

In summary, I have argued in this final chapter that key aspects of patient-centred care with children are both engagement with children's views and experiences, and also acknowledgement of the extent to which children already share responsibility for their care with adults in domestic settings.

That barriers to the achievement of patient-centred care with children cluster around ways in which we think about children and childhood indicates that purely mechanistic approaches to facilitating patient-centred care with children run the risk of becoming instruments of coercion and manipulation. The way forward lies in the integration into care of models of childhood which recognise both the impact on children's lives of their low social status, and the expertise which children have about their own lives. Alongside insights from social studies of children's experiences of their illness and care, such understandings can pave the way for the development of new, multidisciplinary ways of working with children with long-term illness.

7.4.2 Potentially inclusive sections of the Diabetes NSF (Section 3 and Section 5)

> [illegible]

Detailed minutes of the studies that underpin recommendations in the Diabetes NSF are not available in the public domain, however authors of the NSF report that the standards are informed by the views and experiences of people with diabetes. A qualitative study of the views of users of diabetes services was commissioned by the Department of Health (Hiscock et al. 2001) specifically to inform the development of the Diabetes NSF. No children or teenagers took part in this.

It seems that, despite the rhetoric, at least in the field of paediatric type 1 diabetes, the government's call for patient centred working with children does not for the moment, extend to their own practice in the compilation of guidelines. This may be an example of what I argued [illegible] in the chapter that without shifts in ways of thinking about children, calls for participation are likely to be empty rhetoric, and exercises in [illegible] [illegible].

7.5 Summary

In summary, I have argued in this final chapter that key prerequisites for patient centred care with children are both engagement with children's views and experiences, and also acknowledgement of the extent to which children already make [illegible] for their own [illegible], in domestic settings

Appendix 1: information leaflet for children To be read as folded A5 leaflet [size shown is smaller than the original]

Sometimes people feel sad when they talk about their life. If that happened to you I could put you in touch with someone who might be able to help you.

If anything happens in this project that you do not like please tell me, or Dr Allgrove.

If you decide to take part, I will send you a booklet at the end about what everyone said, or a bigger book if you liked.

How to find out more

If you want to find out more, ask your mum or dad to give me a ring on 7040 5934 or 07956 001 668. I will also be in clinics soon to answer your questions. If you decide not to take part, no one will mind.

I only speak English. Let me know if you would like someone who speaks your first language to come to our first few meetings.

Katherine Curtis
City University, 24 Chiswell St, London EC1Y 4YT
Tel 020 7040 5934 or 07956 001 668
email: k.curtis@city.ac.uk

The North East London Health Authority Ethics committee works to make sure that projects like this one are alright for people to take part in. They have approved this project.

Living with diabetes

This leaflet is for children aged 3 to 10 years old (and for your mummy or daddy too, if you want). It tells you about my research project.

It will help you decide whether you want to take part or not.

My name is Katherine.

My job is finding out about what children think about things.

I want to find out how children look after their diabetes. I would like to talk to you about how you look after yourself and your diabetes.

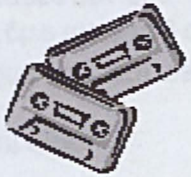
What happens if you take part?

I would like to meet you at least two times – with your mummy or daddy too if you liked.

We would play games and you could do activities like drawing or take photos. We would talk about what you think.

I could come to your home or somewhere else if you liked. We would spend as long or as short a time on it as you wanted.

I would like to make a tape of what you say.



Your name would be kept secret. Only I would know it was you talking.

The only time I might not be able to keep your name secret would be if I thought you or someone else was in danger of being hurt. This might be if you said something or took a photo that made me worried someone was in danger. I would always talk to you first, before talking to someone else about this.

I would also like to watch some of your meetings with Dr Allgrove. I would sit quietly and not say anything. I would leave if you asked me to.

At the end of the project you could meet up with other children who took part, but only if you wanted to. You could all tell me what you thought about the project.

What happens to what children say?

I want to put what children say in a book to show people who plan health services. If you did drawings or writing, or took photographs, I might ask you if I could make a copy for the book. I would only put them in if you said I could.

You could stop ANYTIME

If you did not want to answer a question, just tell me to stop. I would not ask you why. We would just go onto the next question.

You could stop taking part in the project at anytime, just tell me. You do not have to say why.

If you do not take part no one will mind.

It will not change how Dr [illegible] looks after you.

Appendix 2: Child Protection and Serious Danger Protocol

The diabetes clinic provides patients with details of both local and national agencies providing information and/or support to children with diabetes. If participants become distressed in the course of the research - which can sometimes happen when people talk about their lives - as part of her response to this, the researcher will remind participants of the contact details for these agencies.

This protocol is intended to cover situations where the researcher is provided with or becomes aware of information that raises concerns about the safety or welfare of someone who is under16 years old.

As far as possible it is preferable for the researcher to support the child in seeking help from an appropriate adult his/herself. However her responsibility to report serious concerns of harm means that it would be misleading to pretend to the child that it is up to him/her whether the matter is taken further, though the researcher will be as sensitive about this as possible.

Furthermore, in the following circumstances, it would not be possible to speak to the child before taking advice from key contacts (see below):

- If the researcher needs to take advice from one of the key contacts before taking action;
- If the child describes danger posed by a source within the domestic setting (since it would not be sensible to ask the child to discuss this at length during a visit held in that setting).

Finally if the interview is with a parent, carer or professional, the researcher will not say anything to them if she judges that this will further threaten the child's safety.

In light of these considerations, these are the steps the researcher will take if she is provided with or becomes aware of information that raises concerns about the safety or welfare of someone who is under16 years old.

(1) She will use her judgement as to whether or not she should discuss her concerns with the child/participant. If she does she will:

(i) ask whether there are any other grown-ups/any one else who knows about this
(ii) explain that she will need to discuss these concerns with 'someone from my work who knows a lot about children who are in the same situation as you'
(iii) if the danger is from a source outside the domestic environment, say to the child 'I need you to talk about this with someone who cares about you. We need to go together and talk to your (carer) about this, so that they can make sure you are safe.' She will listen to the child's views on this course of action and try to allay any fears s/he may have about it.
(iv) The researcher will keep the child updated - by personal visit, by telephone or other means - of the outcome of discussions with key contacts, if this is possible without endangering the child further, and the child agrees.

(2) The researcher will contact XX (land line / mobile no) or XX (land line/ mobile no) within an hour of the interview in order to decide whether a referral to Social Services is necessary. Either XX or XX will make the final decision as to whether the case will be referred to Social Services or not.

(3) If it is decided that a referral is necessary this will be made within 24 hours of initial contact with the child. Relevant information and reasons for concerns will be passed to the local Social Service Duty Officer. Any referral made to the Social Services Department in these circumstances will be followed up in writing also within 24 hours.

Appendix 3: Safety of researcher in the field

The researcher must consider her own safety at all times during fieldwork. She will follow this protocol:

- Fieldwork will be planned with due consideration to potential risks
- The researcher will avoid the use of inappropriate or provocative language and behaviour that might increase risk
- The researcher must avoid becoming involved in issues that are beyond the boundaries of her competences
- The researcher will always carry a mobile phone when out on fieldwork
- The researcher will appoint an agreed point of contact each time she makes a visit to a private home. This person will hold the address and phone number of where she is visiting that day. The researcher will ring at an appointed time to say that the visit has been completed successfully.

Appendix 4: Invitation to take part in fieldwork

[Headed hospital notepaper]
[Date]

Dear [name of **child** and parent(s)]

Living with diabetes

I am writing to ask you if you would like to take part in a research project.

This would involve the researcher, Katherine meeting up with you (definitely no needles) two or three times this year to talk and play activities to find out more about how you look after your diabetes. She would meet at your home or at the outpatient clinic, whichever you prefer.

The leaflets give you more details about the project. The aim is to find out about the kinds of diabetes care you find helpful, or unhelpful. We hope the research reports will enable many children, parents and carers, and diabetes health care staff to learn more about the kinds of diabetes care that children, parents and carers find most helpful.

If you are interested, please post back the reply slip or contact Katherine. If you leave a message she will call you. I have not told her your names, to protect your privacy. Katherine will be available in clinics soon to answer any questions you might have about the study.

Katherine speaks only English. If you would like someone who speaks your first language to accompany her on your first few meetings, please tick the box on the reply slip, or tell her in the clinic. You do not need to decide whether or not you want to do the study until after you have had the chance to ask further questions at the first meeting.

Please take as much time as you need to think about this letter. Although, if you are interested, we'd be grateful if you would contact Katherine fairly soon.

I leave it to you to decide if you want to help with the research. Whether you decide 'yes' or 'no', we will go on giving you the best care that we can.

Yours sincerely,

Enclose: reply slip and sae, information leaflets

Reply slip:

To: Katherine Curtis
City University, 24 Chiswell St, London EC1T 7TY
tel. 020 7040 5934 or 07956 001 668; k.curtis@city.ac.uk

I would like to know more about the research project:

My name is ....

My parent's name is ....

Address ....

Telephone. Home....................... Mobile ....

Email ....

Please tick the box if you would like someone who speaks your first language to accompany Katherine on your first few meetings

☐ My first language is ....

Appendix 5: Interview guide

The schedule is a guide only. I will pick up cues from what children say and follow their lead and order of topics.

Actions

- First meeting – do info leaflet together; if ok consent form; make clear when I'm talking to child I want to hear child's view; explain want to find out about all aspects of life as all pertinent to managing diabetes
- Subsequent meeting – use prompt sheet to remind re key aspects of taking part and check ok
- Any questions about the project?
- Ask about time child/parent have available.
- Overleaf tick issues covered
- Thanks for taking part.

1. Records

Interview number Interview name

Date of meeting Length Venue Parent present

Child's gender Name of child

Parent(s) name

Siblings (boy/girl - DOB)

Child's DOB Date diabetes suspected/diagnosed

Parent(s) occupation 1/ 2/ Ethnicity

Any other relatives with diabetes (specify type I or II)

What are children's understandings, practices and preferences in relation to managing their diabetes alongside families and clinicians?

2. Important things in your life Discuss photos (or draw) What are the most important things in your life? If appropriate, ask how fit diabetes care round this.

3. Your day
If appropriate enact with Teddy and props (blanket, clothes, tooth brush, food, bowl)
So, you (Teddy) wake up in the morning and what do you do? And then what? Etc etc
Prompt re diabetes care in context of passage of normal day (if appropriate enact with demo kit):
Insulin – when, where inject, who does it, prefs, when children do their own, how long done own, how learn?
Tests – when, who does it, prefs, when do own, how long done own, how learn, what do numbers mean?
Food - when and what, inc snacks, prefs, restrictions, feelings about this in comparison to insulin
Ever forget anything?
At school? Diabetes care? Who helps? Know about diabetes? Ever worried? Snacks? After-school clubs?
How do you/Teddy know if you're high / low / not well? What do you do when you feel that?
How explain about your diabetes to other children/grown ups? Do they ask?
Know other children with diabetes? Like to? Other times away from carer (sleep-overs?) Parties?

4. When you first found out you had diabetes
What happened when you first found out? (tell Teddy - if you can remember)
Hospital - Any nice things? Bad things? (eg first blood test or insulin injection)
Doctors/nurses talk to you or parents? Which prefer? Was it in a way you could understand? What should be different?

5. Going to see the diabetes doctor and nurse
Tell Teddy so he knows what it's like and enact using medical kit or use drawing as prompt
What happens? Do you have to wait? Why?
Who do you see (inc blood nurse / dietician) Why? Helpful? Prefer talk to you / carer? Why? (For school-age children) Do you prefer going there to going to school or do you mind missing school? Why? (For younger) Does Teddy like going to see the diabetes doctor and nurse? Why? What would you like to be different?

6. 'Who decides?' game
Ask children to pick at random photos which might be related to different aspects of diabetes regimen (apple, digestive biscuit, insulin pen, meal of pasta and vegetables, pack of sweets, child riding bicycle, finger pricker). Ask child to stick this on Velcro on A4 laminated card, with pictures in each corner, representing the child, family, a teacher and the doctor respectively. Does this photo remind you of any part of looking after diabetes? What? Who decides when you do this (you, mum/dad, doctor/nurse, teacher – indicate pictures on card)? Why do you have to do it? Who does it? (break down constituent parts eg finger prick, reading/recording BM level)

7. **Top tips** A girl/boy your age / Teddy has just found out he has diabetes… What would you tell him about diabetes? What's the main thing you would tell him/her to help him/her?

8. Is there anything else important about your life or having diabetes that you would like to say?

Appendix 6: Search - children's experiences of asthma: Medline 2007

Database: Ovid MEDLINE(R) <1950 to May Week 1 2007>

Search Strategy:

----

1 exp Nursing Methodology Research/ (9155)

2 (qualitative or ethno$ or emic or etic or phenomenolog$).mp. (72159)

3 (hermeneutic$ or heidegger$ or husserl$ or colaizzi$ or giorgi$ or glaser or strauss).mp. (3710)

4 (van kaam$ or van manen or constant compar$).mp. (998)

5 (focus group$ or grounded theory or narrative analysis or lived experience$ or life experience$).mp. (13590)

6 (theoretical sampl$ or purposive sampl$ or ricoeur or spiegelberg$ or merleau).mp. (1140)

7 (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).mp. (86)

8 (maximum variation or snowball).mp. (436)

9 (field stud$ or field note$ or fieldnote$ or field record$).mp. (6210)

10 (thematic$ adj3 analys$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (1072)

11 (content analy$ or unstructured categor$ or structured categor$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (4614)

12 (participant$ adj3 observ$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (2367)

13 (nonparticipant$ adj3 observ$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (43)

14 (non participant$ adj3 observ$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (133)

15 action research.mp. [mp=title, original title, abstract, name of substance word, subject heading word] (979)

16 exp tape recording/ (11255)

17 (audiorecord$ or taperecord$ or videorecord$ or videotap$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (13589)

18 ((audio or tape or video$) adj5 record$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (26547)

19 ((audio$ or tape$ or video$) adj5 interview$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (2540)

20 or/1-19 (129657)

21 (child$ or infant$ or pre-teen$ or pre-adolescen$ or pediatric$ or paediatric$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (1740352)

22 asthma$.mp. [mp=title, original title, abstract, name of substance word, subject heading word] (96430)

23 limit 22 to yr="1980 - 2007" (77274)

24 20 and 21 and 23 (308)

Appendix 7: Field experts consulted on studies relevant to review

Process of selection

I consulted members of the NICE advisory committees for 'Guidelines on the diagnosis and management of type 1 diabetes in children and young people' and 'Technology appraisal guidance: inhaler devices for the routine treatment of chronic asthma in older children (aged 5 – 15 years)'. To avoid wasting people's time, I excluded six economists, two statisticians and three pharmacologists on the basis of their being unlikely to come across qualitative studies in their work. Six others were untraceable (a clinical psychologist, two chief executives, a director of nursing and two patient representatives). In addition I included two external colleagues with extensive expertise in the field. I received responses from all but two experts.

Experts consulted

Jane Adam	Radiologist
Priscilla Alderson	Professor of Childhood Studies
Sunil Angris	General Practitioner
Jeremy Allgrove	Paediatrician
Timothy Barrett	Paediatrician
Carol Black	Consultant Physician
Anna Burt	Research Fellow, National Collaborating Centre for Women's and Children's Health (NCC-WCH)
Bruce Campbell	Consultant Surgeon
Vincent Connolly	Physician
James Cripps	Consumer Representative
Jo Dalton	Specialist Nurse Practitioner, Paediatric Diabetes
Stephen Greene	Paediatrician
Trisha Greenhalgh	Professor of Primary Health Care

Jane Houghton	Nurse Consultant
Mustafa Kapasi	General Practitioner
Alex McNeil	Research Assistant, NCC-WCH
Gill Morgan	Chief Executive
Moira Mugglestone	Deputy Director, NCC-WCH
Gill Regan	Paediatric Dietitian
Sian Richards	Chief Executive
Stephen Saltissi	Consultant Cardiologist
Katy Sutcliffe	Research Fellow
Andrew Stevens	Professor of Public Health
Ray Tallis	Consultant Physician
Russell Viner	Paediatrician
Mary Watkins	Head of Institute of Health Studies
Norman Waugh	Public Health Consultant
Carol Williams	Consumer Representative

Appendix 8: Methodological assessment criteria

STUDY..

	Quality of reporting	***Score***	***Comments***
1	Aims and objectives clearly reported		
2	Adequate description of the context for carrying out the research Eg reasons for doing the study inc 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 soc-demographics of participants inc 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		
	Extent to which findings are rooted in children's own perspectives		
10	Use of appropriate data collection methods for helping children to express their views		
11	Use of appropriate methods for ensuring the data analysis grounded in the views of children		
12	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

Appendix 9: Example of textual summary

Rudestam et al. 2005

Rudestam's study with 26 children with and without asthma – mainly from disadvantaged backgrounds – in Rhode Island USA, set out to explore children's understandings of their illness, how it affects their perceptions of their environment and how these, in turn affect their daily life. Children described their illness as an external force that induced feelings of powerlessness. They mainly described using reactive, rather than preventative techniques to manage it, such as resting, using the inhaler, drinking water or going to hospital. Children either reported that they did not know what asthma was or gave explanations based on their personal experiences. They experienced it as disrupting and restricting their lives, both because of having to cease physical activity and rest sometimes and because of getting ill and having to go to hospital. Children emphasised that asthma restricts time they can spend outside (pollen, pets and the weather were mentioned as triggers), time spent active (sports and other physical activities such as dancing were mentioned as triggers) and time spent with friends, because of the amount of time peers spend engaged in physical activity or outside. Children felt their asthma made them more vulnerable in certain environments, such as 'dusty' or 'dirty' places; and, compared with children without asthma, preferred places with family members, rather than peers. Children with asthma emphasised the importance of familiar places, over new environments and did not like being alone in case of getting 'sick'. They identified places as 'safe' in terms of containing asthma triggers or not, whereas children without asthma described finding places safe or unsafe because of violence. Finding show how children understand their illness in terms of their personal experiences rather than biomedical models; how far-reaching children's experiences of asthma can be; the importance of education and support for children to help them feel more empowered about managing their asthma; and developing cleaner, less polluted inner-city environments.

Appendix 10: Summary of methods of studies included in review

** for the sake of brevity I have shortened the names of studies to first author and date*

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of data analysis methods
*Walsh 1983	Descriptive study collecting quantitative and qualitative data from 61 children with asthma in Minnesota and Central Iowa on their experiences of their asthma	*Sampling frame:* Attendees of an asthma camp in Minnesota *Selection:* 7-12 year-olds sleeping in selected cabins at camp *Recruitment:* Researcher obtained a list of camp attendees and sent the parents of all 7-12 year-old children written information about the study prior to start of camp *Consent:* written consent from parents prior to start of or at asthma camp (all agreed); children's assent requested day prior to interview (85% agreed)	Semi-structured individual interviews 30-40 minutes in length carried out to explore children's feelings and experiences of asthma; Piers Harris Children's Self Concept Scale administered. Researcher also had access to child health records submitted by parents and physicians to the camp sponsor, the American Lung Association, a log of children's visits to the camp health services and the primary camp nurse's reports on children during their stay.	*Reliability:* Not described *Validity:* Interview pre-tested with similar age children and reviewed by experts; tape recorded; children free to initiate questions and topics; tried to help them relax with drawing task at start of interview	Data sorted into categories arising from data and further summarised using constant comparative method	*Reliability:* Not described *Validity:* Used contributor's terms in reporting
Spezia 1991	Descriptive study collecting qualitative data from members of 7 families (plus pilot) with an 8-12 year-old IDDM child attending a diabetes support group or cared for by a paediatrician in SE Missouri on children's self-care activities and the interrelationships between and among family members and larger social units	*Sampling frame:* Attendees of a pediatric diabetes support group; or families whose diabetic child is cared for by specified pediatrician in SE Missouri *Selection:* Convenience sample of members of families with an 8-12 year diabetic old child diagnosed at least a year ago, on insulin therapy, who participates in school/social activities with peers, whose family is aware of their diabetes-related needs, who is under the care of a physician, and who regularly tests or is tested for (blood or urine) glucose levels *Recruitment:* Recruited from several support group meetings. Families also contacted by	Semi-structured interview with children, parents and siblings; collection of demographic data from parents via written questionnaire	*Reliability:* Main theoretical ideas drawn from nursing theory; ideas about children not explicit, though deficit model of children's capabilities apparent in description of children's limitations in providing 'comprehensive descriptions' *Validity:* questions for children checked by experienced colleagues; questions piloted; children prompted as to whether there is 'anything else you'd like to tell me'; interviews taped; accuracy of transcriptions checked by researcher; story about imaginary camping trip included to help children express themselves; information from field notes/ interviews and data from parents/children triangulated.	Thematic content analysis used to identify categories in the data and transcriptions reviewed to identify and code major categories, subcategories and themes.	*Reliablity:* Used 'Ethnograph' to manage qualitative data and matrices to display *Validity:* Exploration of depth using contributor's terms; demonstration of range of views via inclusion of vignettes appended with participant details

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of data analysis methods
		pediatrician's office with a description of study and request to phone researcher if they wanted to take part. *Consent:* Written consent from parent and child for under 14s				
Zahorik 1991	Descriptive study collecting qualitative data from 26 6-12 year-old diabetic children attending a diabetes clinic in NE Ohio on their understanding and experiences of, and coping strategies for managing their illness	*Sampling frame:* Attendees of a diabetic out-patient clinic at university medical centre serving NE Ohio. *Selection:* Diabetic children aged 7-12 years diagnosed for at least 6 months at time of first interview *Recruitment::* A list of all children at diabetes clinic obtained and 56 letters sent to parents of children who fulfilled above criteria to say that they would be contacted by phone to obtain verbal permission and arrange an interview time; (those with physical illness or whose parents requested exclusion from university projects were not contacted) *Consent:* Written consent from child and accompanying adult (one interview abandoned when child declined consent after extensive wait to see physician)	Two open-ended interviews at the clinic during scheduled diabetic visits (3-9 months apart) with some open-ended weekly telephone interviews in-between (average 13 per child). Principal investigator carried out 16 initial Interviews and all final interviews. Graduate student conducted the rest.	*Reliability:* Reported that a reliability check carried out to assure range of congruence in data gathering but no further details given *Validity:* some parents reported that children enjoyed the interviews, looked forward to the weekly telephone calls and gave information they did not share with them, but researcher did not use this as starting point for more detailed reflection on impact of methods of data collection	Data was coded (no description of how)	*Reliability:* Reported that a reliability check carried out to assure range of congruence in data coding but no further details given *Validity:* Not described
Ireland 1997	Descriptive study collecting qualitative data from 10 9-12 year-old asthmatic children on their perceptions of having asthma	*Sampling frame:* Not explicit but likely to be attendees of a specific UK hospital asthma clinic *Selection:* Purposeful selection of equal numbers of boys and girls aged 9-11 years with a diagnosis of asthma made at least 1 year ago	Interviews started with 'grand tour' question of 'tell me what having asthma is like for you', followed by prompt questions to explore children's experiences	*Reliability:* Underpinned by idea that understanding may evolve with experience rather than solely with chronological age; reflected that children felt able to ask for clarification when unsure about questions and correct interviewer's misconceptions and showed pride in their explanations of their experiences *Validity:* interview guide delivered	Transcripts read and re-read and then coded by researcher by labelling data and then comparing with other data to identify recurring themes and patterns.	*Reliability:* Data coding checked by two independent raters *Validity:* Interviews transcribed in full as soon as possible after recording; limited use of contributors' terms in report of findings

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of data analysis methods
		Recruitment: Invitation to parents sent, child's invitation enclosed *Consent:* Parents and children gave written consent – child's willingness to consent double-checked when parent first expressed interest in taking part		flexibly, in child-friendly language and accounting for children's differing attention-spans; researcher emphasised this is not a test; interviews recorded; respondent validation via discussion of interviews with children and opportunity for them to confirm or query what they'd said		
Miller 1999	Descriptive study collecting qualitative data from 6 7-12 year-old diabetic children and their parents in UK on children's experiences of diabetes	*Sampling frame:* Described only as '8 diabetic children' and '1 family known to the researcher' where child is 7 to 12 years-old *Selection:* Not described *Recruitment:* Letter sent to parents with request to pass attached letter to child if they were willing for the child to participate *Consent:* Parental consent, child assent. 'Each family signed a consent form'	Conversations with children were held in private in a place agreeable to parents and child, 5 out of 6 times in children's home. 'It was necessary to have appropriate questions to ask the children to help them tell their story… prompt questions aimed to help the children focus on specific events and situations'	*Reliability:* Theoretical underpinning described only in terms of methodology (phenomenology) but some indication of influence of ideas from sociology of childhood in insistence on focusing on the child's perspective for its own sake *Validity:* Interviews taped; children asked to draw a picture to help them relax; flexible approach to interviews with children and subjects familiar to children eg 'what is your normal day'; familiar interview surroundings	Reading and re-reading transcripts to familiarise; data labelled and categorised to identify key themes using, where possible, children's own words. Developing themes double checked against original data	*Reliability:* Not described *Validity:* Efforts to stay close to original data, developing themes double checked against original data; some use of contributor's terms
Meng 2002	Descriptive study collecting qualitative data from 28 children 7-12 years and 21 parents at USA asthma camp on children's decision-making about asthma treatments	*Sampling frame:* Children at USA asthma education camp *Selection:* All who agreed to take part (not clear if age range was a condition of selection or not) *Recruitment:* 'Children asked to return for post-camp focus group discussions' *Consent:* Parents signed consent forms	Focus groups each with seven or eight participants held on a large medical centre campus at the School of Nursing; participants urged to 'think back' to place themselves in their imagination in the original situations they were asked about; questions asked about their worries about asthma, about sharing care with parents or other adults, about checking correct ways of taking medication and responses to triggers	*Reliability:* Not explicit, but theoretical underpinning appears to be drawn from developmental psychology; description of moderators included (two nurses and a pulmonary functions expert, two of whom were known to children as asthma camp staff, none with previous experience of moderating focus groups) *Validity:* 'developmentally appropriate' words used in interviews with children; moderators explained no 'right or wrong answers'; interviews taped; guarantee of confidentiality (with child protection proviso) reiterated at start of interview;	Tapes transcribed; data labelled and categorised on basis of themes arising from data; frequencies counted; conflicting accounts by parents and children compared	*Reliability:* Independent raters *Validity:* Tapes transcribed by experienced transcriber; accuracy checked by researcher; triangulation of data from children and parents; no direct quotations included in report of findings
Pradel 2002	Descriptive study collecting qualitative data from 32 7-12 year-old	*Sampling frame:* Children in two asthma clinics in North Carolina, [a] one in a large teaching hospital [b] the other in	Data collection at children's home; intervention of parents avoided to get children's views only; unstructured interview	*Reliability:* Theoretical underpinning drawn from developmental psychology whereby understanding and knowledge acquisition follows a defined age-related	Unstructured interviews analysed using content analysis: categories drawn from list of themes selected	Reliability: *Description of data management tools though extent to which qualitative data*

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of *data analysis methods*
	children with asthma in North Carolina on their asthma knowledge, perceptions and autonomy and how these vary with age	a community centre *Selected:* children with moderate/severe asthma aged 7 or 12 years and within 6 months of their birth date though not clear how selection carried out *Recruitment:* [a] Researcher approached families in person; [b] families sent invitation from the head of the Pediatrics Dept and the researcher; families were then telephoned to find out if they wanted to take part *Consent:* [a] 'informal consent gained from parent and child' after participation agreed; [b] not described	exploring aetiology of illness, symptoms, restrictions, management, recovery and social environment; child asked to draw a time they did not feel well (researcher notes whether or not asthma episode selected); second instrument required children to describe the process of an asthma attack in terms of symptoms experienced and action taken before and after the attack: child shown point on a line indicating a time s/he had an attack and asked to describe what happened at the time of the attack, before and afterwards and researcher noted information about each point in time on time-line	hierarchical progression; also Health Belief Model, whereby individual's propensity to engage in health-related behaviour is mediated by perception of severity of illness; interviewer identified as first author (pharmacist); *Validity:* Children reassured 'they were not taking a test', and could stop interview whenever they wanted; familiar interview surroundings; interviews taped though one not transcribed as inaudible	by researchers in related studies internationally; data pertaining to each theme collated in word processor files; data from time line interview coded by symptom and management responses, and frequencies for each category entered into SPSS; across both instruments frequencies of answers for the two age groups counted	*tabulation facilitated within and across case analysis questionable* Validity: *Triangulation of data from two instruments; demonstration of depth by use of contributor's terms, though no indication of range of views as details of participants/code name not included*
Sutcliffe 2003	Descriptive study collecting qualitative data from 24 3-12 year-old diabetic children, 29 parents and 4 specialist diabetes clinicians in London and SE England on children's views of their diabetes and sharing their care with adults. Comprised of sub-studies a] and b]	*Sampling frame:* children attending 3 diabetes clinics: a] one in a disadvantaged and ethnically diverse area of SE London, another in an advantaged Surrey commuter town; b] the third in a disadvantaged and ethnically diverse area in East London *Selection:* a] purposive selection of 3-6 and 10-12 year-old children and their parents to include a range of ethnicities, SES background and experiences of diabetes; b] convenience sample of 6-11 year-olds *Recruitment* : a] Clinic staff sent information letters, invitations and reply slips with researcher	Semi-structured interviews a] Most families interviewed at home, mostly altogether. b] Families interviewed in private room at clinic mostly with parents present and a few (by their own choice) in pairs. Some children across both sub-studies chose to use drawing materials and provided a picture; and a few younger ones used play materials Two observations also carried out of clinic sessions	*Reliability:* Theoretical underpinning influenced by childhood studies approach which values children's views for their own sake and looks for potential competencies rather than deficits; description of settings/sample indicates potential for transferability; *Validity:* Family interview schedule piloted; all interviews tape taped with the exception of one where child requested note-taking; use of draw / play methods, flexible use of interview guide and subjects familiar to children ('what did you do today') to help them express themselves; children reassured they could refuse questions if they wanted and end the interview at any point if they wished;	Reading and re-reading transcripts and observations; analysis carried out using constant comparative method	*Reliability:* Constant comparative method, (incorporates search for difference as well as similarity) *Validity:* thick descriptio and extensive use of contributors' terms; inclusion of code names t demonstrate range of perspectives; triangulatio of data from children /parents /clinicians

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of data analysis methods
		contact details; in SE London clinic researchers sent postal reminders; b] Families invited to take part by researcher when attending the diabetes clinic *Consent:* Not described				
Nabors 2003	Descriptive study collecting quantitative and qualitative data from105 5-14 year-old children with type 1 diabetes in Midwestern USA on their perceptions of diabetes support at school	*Sampling frame:* 2 summer camps in Midwestern USA *Selection:* Not described *Recruitment:* Parents approached when they brought their child to camp *Consent:* Parental consent and child assent (copy of consent form, study procedures and measures provided to parent only)	Written questionnaire for parents about child's diabetes; children completed structured questionnaire on the amount of support needed from teachers, nurses, friends and parents in looking after their diabetes at school; discussion groups held using Nominal Group Technique whereby each child must give a response to each question and also indicates their dis/agreement with peers' responses.	*Reliability:* Interviewers described (child psychologist, psychology graduate student and medical student). *Validity:* Structured instrument made more child-friendly by using smiley faces on rating scales for younger children; Not clear how group data recorded	Constant comparative analysis used to analyse data from groups and interviews; qualitative data also coded as representing a positive or negative statement about support at school	*Reliability:* Constant comparative method, (incorporates search for difference as well as similarity) *Validity:* independent raters; extremely limited reporting of children's views in their own words
Dell Clark 2003 (B)	Descriptive / ethnographic study collecting qualitative data from 10 7-10 year-olds and 36 5-8 year-old asthmatic/diabetic children and their families in or around Chicago on children's experiences of their illness	*Sampling frame:* Not described *Selection:* Children with diabetes or severe asthma aged (pilot) 7-10 years, (main study) 5-8 years were selected (to achieve a sample stratified by age and gender – personal communication) but no description of how *Recruitment:* By a professional recruitment firm, screened via a telephone questionnaire to establish if child met study's definition of having diabetes or asthma; parents of asthmatic children screened again in interview to establish severity of illness *Consent:* Not described	Two home visits approximately 2-3 months apart. Parents (usually mothers) kept note-book diary of observations about the children's lives for period between the two visits; interviews comprised 'session on play, into which talk was inserted'; used props eg dolls, doctors kit, miniature model hospital, drawing materials, Metaphor Sort Technique: children use photographs to describe their feelings about their illness and its treatments; children in main study given single use camera so photos used as basis to show and tell about their illness in second interview	*Reliability:* Theoretical underpinning influenced by childhood studies which values children's views for their own sake and looks for potential competencies not deficits; children eager for second interview; *Validity:* pilot interviews with 10 families (included in findings); interviews taped; children could control taping; familiar interview surroundings; interviewer presented self as 'on a level': open, respectful and wanting to learn from children's expertise about their lives; used instruments flexibly; interviews based in familiar activities;	Not described	*Reliability:* Not described *Validity:* Triangulation of data from children /parents and range of approaches to data collection; some thick description though author's assertions in diabetes section of report not routinely accompanied by supporting first order data from children

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of data analysis methods
Koinis-Mitchell 2003	Descriptive short-term (two-year) longitudinal study collecting qualitative and quantitative data from 31 7-12 year-olds and their families in Massachusetts in order to examine associations between levels of self-competence, asthma knowledge, and asthma-management behaviours	*Sampling frame:* Families using one of 5 community health centres in Dorchester or Roxbury MA. *Selection:* Children aged 8-10 years diagnosed with asthma, living in Dorchester or Roxbury MA, with sufficient English speaking skills to take part in a 2 hour interview; and a volunteering primary caregiver who is the child's legal guardian and who has lived in the same household as the child for at least the past year *Recruitment:* Community health staff invited families with asthmatic children aged 8-10 (not stated how) or researcher approached mothers in health centre waiting rooms to fill out 'consent to be contacted' forms. Researcher then telephoned interested families with further details of study and to screen for inclusion (see criteria above) *Consent:* Parents signed consent forms for themselves and their children; children signed assent forms	Children and families attended 'a comfortably furnished laboratory' at the university for 2 2-hour sessions, 9-15 months apart. Parent and child interviewed simultaneously and apart for 2.5 hours. Data-collection with children comprised completion of 4 quantitative instruments to measure psychosocial and illness-related functioning, 4 quantitative instruments collecting descriptive data and a qualitative interview on children's feelings about having asthma. At follow-up data collection was reduced to 1 hour; two families chose postal questionnaire and one chose telephone interview instead of face-to-face meetings.	*Reliability:* Theoretical basis in developmental psychology; 2 families did not consent to follow-up interviews and a child from a third family was ill at follow up (the family did not respond to researchers' requests for rescheduling), therefore only 28 children of 31 took part in second data collection. *Validity:* Interviews audio-taped; on first occasion, child interviews led by graduate student with several years 'child assessment' experience who used several introductory questions 'to make him/her feel comfortable; amended some procedures for second data collection in light of feedback from participants	Correlational analyses were carried out to identify relationships between quantitative variables. Qualitative data analysed using a 'descriptive' analysis based on a exploratory coding scheme developed by research team	*Reliability:* Processes of qualitative data analysis unclear *Validity:* Good reporting of children's views in their own words though no indication of range of views as details of participants/code names not included
Boyle 2004	Descriptive study collecting qualitative data from 19 asthmatic school children, 4 mothers and 18 school staff in SE USA on their beliefs about and management of their illness	*Sampling frame:* Children attending an African-American elementary school in SE USA *Selection:* All children identified by parents as having 'breathing problems' on a health information card completed at the beginning of the school year, who had not subsequently left the school and with whose	Focus groups conducted in the school library included questions for children about what it feels like to have asthma, what they do when they have an attack, what causes an attack, what makes the asthma worse, what medicine is taken for the asthma. Questions for parents and teachers included	*Reliability:* Not described *Validity:* Efforts made to ensure setting conducive to open discussion, refreshments served; interviews taped	Data categorised and emerging themes identified	*Reliability:* 'Ethnograph' used to manage data; *Validity:* triangulation of data from different sources; limited inclusion of children's own words in report of findings

Study	Study design summary	Sampling, recruitment, consent	Data collection methods	Reliability and validity of data collection methods	Data analysis methods	Reliability and validity of data analysis methods
		parents the researcher was able to make contact *Recruitment:* Parents of eligible children telephoned with invitation for child to take part *Consent:* Written consent from parents, assent from children	problems they have experienced in managing children's asthma			
Rudestam 2005	Descriptive study collecting qualitative data from 14 children with asthma (and further 12 in control group who did not have asthma) in Providence, Rhode Island on their understanding of their sense of place	*Sampling frame:* (asthma group) attendees of elementary school arm of asthma education project *Selection:* (asthma group) not described *Recruitment::* (asthma group) not described *Consent:* not described	(asthma group) Children interviewed for approximately 20 minutes; parents sometimes attended interview; open-ended questions on favourite activities, activities carried out outside, understanding of asthma and triggers, and how asthma might prevent children's enjoyment of place	*Reliability:* All children seemed to appreciate attention given to their personal experiences *Validity:* 6 asthmatic children agreed for interview to be taped, records of all other interviews made using notes; pictures used as prompts; interviewer let children lead course of interview	Coded and identified recurring themes and relationships; developed categories both from observational notes and taped interviews	*Reliability:* Not described *Validity:* Demonstration of depth of analysis via thick description / use of contributor's terms

Appendix 11: Summary of studies included in review

** for the sake of brevity I have shortened the names of studies to first author and date*

Study	Aims	Characteristics of children in sample	Summary of findings on children's experiences of illness	Methodological assessment criteria satisfied for purposes of this review
Walsh 1983*	To provide a systematic description of the school-age child's experience of asthma, specifically to elicit and examine the definitions, explanations and feelings about both the chronic and acute aspects of the asthma experience from the perspective of the school-age child who has asthma	***Location:*** Minnesota and N Central Iowa (half within the greater metropolitan area of Minneapolis-St.Paul) ***Sample number:*** 61 ***Age:*** 7-12 ***Sex:*** 30 girls and 31 boys ***Class:*** An even spread across range of SES ***Ethnicity:*** 52 Caucasian, 9 Black ***Illness:*** 29 moderate, 22 severe, 9 mild asthma ***Recruited via:*** Asthma camp ***Exclusions:*** None stated ***Other participants:*** None	Some children used very definite, negative descriptors about their experiences. The experience of difference included feeling isolated, being teased, experiencing differential treatment in the form of both restrictions and attention, and being aware of the financial and emotional cost of having asthma.	1, 2, 3, 4, 5, 7, 9, 10, 11
Zahorik 1991	To gain an understanding of how children with juvenile diabetes: explain and manage their condition; explore their participation in managing the illness; determine if they are meaningful informants on health and illness issues; and lend support to the benefits of eliciting their beliefs and analysing their behaviours	***Location:*** NE Ohio ***Sample number:*** 26 ***Age range:*** 6-12 years ***Sex:*** 15 girls, 11 boys ***Class:*** Not known ***Ethnicity:*** 6 Black, 20 White ***Illness:*** Diabetes diagnosed for at least 6 months at time of first interview ***Exclusions:*** Children with physical problems such as deafness or whose families requested exclusion from hospital projects	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.	1, 2, 4, 6
Spezia 1991	To gain a comprehensive understanding of the self-care activities of school-age children with type 1 diabetes	***Location:*** Rural SE Missouri or S Illinois (Midwestern USA) ***Sample number:*** 7 ***Age range:*** 9-12 ***Sex:*** 3 girls and 4 boys ***Class:*** Middle income ***Ethnicity:*** 7 Caucasian	Self-care activities included learning about diabetes, knowing insulin dosages, drawing up and administering insulin, monitoring glucose levels, maintaining dietary	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11

Study	Aims	Characteristics of children in sample	Summary of findings on children's experiences of illness	Methodological assessment criteria satisfied for purposes of this review
		Illness: IDDM type 1 diabetes diagnosed for 1 year or more ***Recruited via:*** Juvenile diabetes support group and 2 paediatricians ***Exclusions:*** None stated ***Other participants:*** 7 mothers, 7 fathers, 6 sibs (mean age 12.7)	practices, exercising and assuming a degree of responsibility and decision-making.	
Ireland 1997	To examine children's perceptions of having asthma	***Location:*** UK ***Sample number:*** 10 ***Age range:*** 9-12 ***Sex:*** 5 girls and 5 boys ***Class:*** Not described ***Ethnicity:*** Not described ***Illness:*** Asthma diagnosis for at least one year ***Recruitment via:*** Not explicit but may be hospital asthma clinic ***Exclusions:*** none ***Other participants:*** None	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 sub-optimal control.	1, 2, 4, 5, 6, 7, 8, 9, 10, 11
Miller 1999	To describe the lived experience of children with IDDM	***Location:*** UK ***Sample number:*** 6 ***Age range:*** 7-12 ***Sex:*** 2 girls and 4 boys ***Class:*** Not described ***Ethnicity:*** Not described ***Illness:*** IDDM ***Recruited via:*** Not described ***Exclusions:*** None stated ***Other participants:*** One or both of each child's parents	Findings describe children's feelings on diagnosis, on their daily diabetes regimen, on being normal, on good and bad things about having diabetes, and on sources of support.	1, 2, 4, 5, 6, 7, 9, 10, 11

Study	Aims	Characteristics of children in sample	Summary of findings on children's experiences of illness	Methodological assessment criteria satisfied for purposes of this review
Meng 2002	To learn how children with asthma and their parents make treatment-related decisions	***Location:*** USA ***Sample number:*** 28 ***Age range:*** 7-12 ***Sex:*** 11 girls and 17 boys ***Class:*** Not described ***Ethnicity:*** 15 African-American and 13 Caucasian ***Illness:*** Moderate – severe asthma ***Recruited via:*** Asthma camp ***Exclusions:*** None stated ***Other participants:*** 21 parents	Children's decisions to medicate are guided by the presence of symptoms. Trigger avoidance and early warning signs tend to be overlooked.	1, 2, 4, 5, 7, 8, 10, 11
Pradel 2002	To explore the knowledge, perceptions and autonomy of 7- and 12-year-old children relative to the management of their asthma	***Location:*** N. Carolina, USA ***Sample number:*** 32 ***Age range:*** 7-12 ***Sex:*** 12 girls and 20 boys ***Class:*** socially diverse ***Ethnicity:*** 15 Black, 16 White, 1 Native American ***Illness:*** Moderate - severe asthma ***Recruited via:*** 2 asthma clinics in a large teaching hospital and community centre respectively ***Exclusions:*** None stated ***Other participants:*** None	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.	1, 2, 3, 4, 5, 7, 10
Koinis-Mitchell 2003	To examine the associations between levels of self-competence, asthma knowledge, and asthma-management behaviour and their concurrent and longitudinal relationships with two mo of functioning: asthma-related and psychosocial functioning	***Location:*** Dorchester and Roxbury, Massachusetts, USA ***Sample no:*** 31 @ year 1, 28 @ year 2 ***Age range:*** 7-10 (at commencement of fieldwork) ***Sex:*** 16 girls, 15 boys ***Class:*** Diverse, with 24 families on or below poverty threshold ***Ethnicity:*** 21 Black, 1 White, 6 Hispanic, 1 American Indian, 2 Multi-racial ***Illness:*** Asthma diagnosed by a physician ***Recruited via:*** 5 urban community health care centers	Findings revealed children's understandings of what it means to do well in their asthma care and what makes caring for their asthma more and less difficult.	1, 2, 3, 4, 6, 7, 9

Study	Aims	Characteristics of children in sample	Summary of findings on children's experiences of illness	Methodological assessment criteria satisfied for purposes of this review
		Exclusions: None stated ***Other participants:*** children's primary care givers		
Sutcliffe 2003 (A)	1] To elicit children's views about thei diabetes 2] to explore they ways they share in their health care 3] provide information on their views about coping and living with diabetes and sharing care with concerned adults	***Location:*** East and South East London and a commuter town in South East England ***Sample number:*** 24 ***Age range:*** 3-12 ***Sex:*** 10 girls and 14 boys ***Class:*** Diverse (study conducted in both affluent and disadvantaged areas) ***Ethnicity:*** 2 Asian, 3 Black, 1 Mixed-race, 18 White (reviewer's categories) ***Illness:*** Type 1 Diabetes ***Recruited via:*** Paediatric diabetes clinics ***Exclusions:*** None stated ***Other participants:*** 21 mothers/7 fathers present/interviewed	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.	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11
Nabors 2003	To examine children's perceptions of support in caring for their type 1 diabetes from school nurses, teachers and friends.	***Location: USA Midwest*** ***Sample number:*** 105 ***Age range:*** 6-14 ***Sex:*** 60 girls and 45 boys ***Class:*** Not given ***Ethnicity:*** 6 African-American and 99 Caucasian ***Illness:*** Type 1 diabetes ***Recruited via:*** Diabetes summer camps ***Exclusions:*** None stated ***Other participants:*** 78 parents completed a survey on children's glucose levels and need for adult support	Children felt supported at school though identified potential for improvements in some areas.	1, 2, 4, 5, 8, 9, 10, 11

Study	Aims	Characteristics of children in sample	Summary of findings on children's experiences of illness	Methodological assessment criteria satisfied for purposes of this review
Dell Clark 2003 (B)	To open a window on the felt human experience of symptoms, suffering and treatment encountered by a cross-section of young children, understood from their own vantage point.	***Location:*** USA Chicago urban and suburban areas ***Sample number:*** 46 ***Age range:*** 5-8 (mainly) ***Sex:*** 23 girls, 23 boys* ***Class:*** Diverse, but not inc many very poor* ***Ethnicity:*** Approx 4 Hispanic/African American; approx 42 White* ***Illness:*** Diabetes or severe asthma ***Recruited via:*** Recruitment company ***Exclusions:*** None stated ***Other participants:*** Some parents kept diaries/were interviewed	Findings describe children's experiences and understandings of their illness, and coping strategies, including stories, play, role-reversal play, humour and ritual.	1, 2, 4, 6, 7, 9, 10
Boyle 2004	To explore beliefs and concerns about asthma and asthma management among school-children (and teachers and carers) and ascertain how they describe asthma and its management	***Location:*** South Eastern USA ***Sample number:*** 19 ***Age range:*** 6-11 ***Sex:*** 10 girls, 9 boys ***Class:*** Study conducted in low income area ***Ethnicity:*** African-American ***Illness:*** Having asthma or 'breathing problems' ***Recruited via:*** *School nurse and school principal who suggested children to approach* ***Exclusions:*** None stated ***Other participants:*** 18 teachers and 4 mothers	Children reported fear of not being able to breathe and the limitations of living with asthma.	1, 2, 3, 4, 5, 7, 8, 10, 11
Rudestam 2005	To explore: 1] how children with asthma understan their illness, especially in terms of thei sense of place 2] the influence of the asthma on environmental attitudes and perceptions	***Location:*** Providence, Rhode Island, USA ***Sample number:*** 14 ***Age range:*** 8-12 ***Sex:*** 9 girls and 5 boys ***Class:*** Poor ***Ethnicity:*** 6 Hispanic, 4 White, 4 African-American ***Illness:*** Moderate – severe asthma	Children experienced 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.	1, 2, 3, 4, 5, 6, 7, 9, 10, 11

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* personal communication

Study	Aims	Characteristics of children in sample	Summary of findings on children's experiences of illness	Methodological assessment criteria satisfied for purposes of this review
	3] how these perceptions influence activities and daily life	***Recruited via:*** School/community asthma programme ***Exclusions:*** None stated ***Other participants:*** 12 children without asthma (mean 10 yrs)		
Fieldwork study	To explore children's experiences, understandings and practices in relation to their diabetes and its care	***Location:*** East London ***Sample number:*** 17 ***Age range:*** 4-11 ***Sex:*** 9 boys and 8 girls ***Class:*** diverse ***Ethnicity:*** 6 Somali, 4 White English, 2 African, 2 Arabic, 1 White British, 1 Bengali British, 1 Eastern European ***Illness:*** Type 1 diabetes ***Recruited via:*** Paediatric diabetes clinics in East London ***Exclusions:*** None ***Other participants:*** None	Children described disruption across physical, psychosocial and emotional spheres as a result of their illness and regimen. Finding the psychosocial resources to meet these challenges can be difficult for those experiencing stress from family social and economic exclusion. Children take steps to minimise the disruption to their lives, and value identities that allow them to accommodate the imperatives of the regimen at the same time as maintaining their sense of being the same as others. Findings from the study support theories which present children's learning as a gradual, accumulative process centring around children's immediate physical and social experiences.	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11

(B) identified via bibliography search; (A) identified by author or expert recommendation; All other review studies identified via database searches
Shaded studies are those that include participants with type 1 diabetes

Appendix 12: Example of data tabulated by theme from studies of minority ethnic children with asthma in USA

[bracketed notes indicate KC's interpretation rather than authors']

Rudestam (8-12 years) **(stronger)** Focus on vulnerability/reliance on family	Koinis-Mitchell (7-10 years)	Pradel (7-12 years) Focus on age/children's knowledge/ (in)competence over experiences	Boyle (6-11 years) Concern re AA boys fear of death and extreme language	Meng (7-12 years) Concern re not avoiding triggers
Interruption and limitation (often children's definition of asthma) 'When you have to stop running because you can't breathe' Spending less time outside (pollen, weather), doing physical activity, and by extension with friends or family (smoke or pets): 'When my asthma's bad my mom won't let me go out and play with my friends, and I feel bad, but she won't let me go outside. . . Everyone else can run around but I can't and it makes me feel bad'; being sick a lot Children liked places free of constraint, where there's 'more room' or where 'I can go wherever I want' but are also safe (children without asthma stressed dangerous urban environments, authors sees them 'trapped by invisible boundaries', prefs mall over 'downtown'); yet children with asthma were less likely to explore isolated or new places than children with asthma	[Although the author did not discuss disruption and limitation these relevant data were listed in appendix] 'Sometimes I can't sleep. I can't chew with my mouth all the way closed.' 'I start wheezing but you really want to play' 'I couldn't play gym, have to take my pump' 'I like playing sports and I can't' 'Stay in bed. Can't do nothing.' 'Dust at home makes it worse'	Impact on life indicated by fact that three-quarters of illness episodes drawn involved asthma; author acknowledges that asthma constrains children's participation in physical activities [Author discusses the following in terms of children's knowledge of triggers but they also indicate children's experiences of these things as causing them disruption] physical activity, other illnesses, environmental triggers like outdoor temperature, weather, pets, dust, pollens, smoke.	One major theme is: You can't do what you want to do They particularly hated restriction on physical activities and author describes an interest in sport and sporting heroes as particularly important for African American children – also disliked not having pets - children expressed remorse about this - - one boy had to give his dog away – they also described being sick a lot, not just going to hospital for asthma but having more coughs and colds in winter	Children described interference with activities of daily living eg: missing school, hospitalisation, interference with sport, with sleep, though this was a secondary worry to their worry about asthma symptoms such as shortness of breath and tightness of chest
Sharing care with family and carrying out independent care children stressed the importance of familiar places that are not isolated and include family members - children with asthma emphasised family members more while children without asthma spoke more about friends being there. Children with asthma seemed more aware of their vulnerability and reliance on others than non-asthmatic children. (Puerto Rico 'because because my family is there and they protect me from stuff')	Children said illness is easier to manage in a familiar home environment with parents around to help. Support from friends and family helps them look after their asthma better 'My mom has a schedule that I should follow, she reminds me.'; helps them feel 'just as good as anyone else' and helps them feel less anxious about their asthma 'At home I feel the most confident because I am with my parents" Doing really well at taking care of your asthma means both 'doing what the doctor says' and looking to mom when something is wrong and following her lead'. **Gaining control by**	Children described managing asthma in collaboration with parents, friends and teachers and most told someone they were sick eg parent/teacher; author says younger children mostly took rest/told mum/ did not know what to do whereas older also did breathing exercises or rested. Majority of 12 yrs olds reported medicating on their own, whereas 7 yr olds' decisions to medicate were made by carers. It was always parents who contacted health profs. Author is concerned because children were not familiar with 'the drug category they should take for treating an asthma attack'.	Older children said their mothers had shown them how to use their inhaler by themselves and younger children said they would not use their inhaler unless they were with their mum.	Over a quarter of children could recognise early warning symptoms though some said they sometimes denied experiencing these and one hid them from others (the author felt both parents and children didn't avoid triggers enough). One relied on parents to recog early symptoms. Some children described requesting parental help managing symptoms, esp when they persist after meds; one child denied needing

Rudestam (8-12 years) **(stronger)** Focus on vulnerability/reliance on family	Koinis-Mitchell (7-10 years)	Pradel (7-12 years) Focus on age/children's knowledge/ (in)competence over experiences	Boyle (6-11 years) Concern re AA boys fear of death and extreme language	Meng (7-12 years) Concern re not avoiding triggers
	knowing what to do yourself is important too - looking after asthma is easier "now I know what to do' , getting older helps 'because you learn more', 'more responsible, can remember things', 'because I know what to do when I start to cough'; knowing about asthma can help you feel in control, responsible, able to do things by yourself and controlling asthma makes you feel 'good/great/proud' (moral framework); children also expressed hope they would 'grow out' of asthma - **compare this taking control data with sense of unpredictability of onset** in Pradel and Boyle)	Only a small proportion of 12 yr olds and even fewer 7 yrs olds specifically reported using quick relief medicine when having an attack tho author acknowledge they might not have realised she was expecting this distinction since the discussion centred on what they would do if they had an asthma attack		parental help
Embodied understandings: Their explanations of asthma were based in their own experiences and they enjoyed sharing these experiential understandings). During the Draw-A-Breath classes children were often distracted or unresponsive to the teacher. But even in the most disruptive classes, when asked to talk about their own asthma, children were immediately eager to share their experiences. They shouted responses like 'I wheeze, I can't breathe.'	[my interpretation to put it in this category, this is just information from the appendix] 'My chest starts to hurt' 'It's hard to breathe'	Children described experiencing physical symptoms, most common, difficulty in breathing, wheezing, feeling bad, throwing up	Children's descriptions were a mixture of physical symptoms and the emotional responses to them… 'It's a scary feeling and it feels bad. It feels like you getting electrocuted.' Medication 'untightened' the lungs	
Knowledge of triggers children preferred clean, trigger free environments and disliked places where there were likely to be triggers (too cold, too hot, dirty, 'my aunt has cats') They also saw physical activity as a trigger and resting 'I lay down' as a useful intervention	['Dust at home makes it worse']	12 yrs olds gave more comprehensive list of triggers than 7 yr olds. Author was concerned that children lack the knowledge to *avoid* things they know to be triggers, though says this might be because this is beyond their control - and doesn't acknowledge that they might *choose* not to avoid.	[children's emphasis on restrictions around physical activity and not having pets indicate they know these are triggers: the author's choice here to focus on children's experiences of restriction whereas Pradel focuses on their knowledge of triggers shows interesting difference of approaches, one more child-centred than the other)	Most could recognise what triggered their asthma though only half of these said they actively chose to avoid these and author felt this was a prob which parents didn't support children in doing either [choice, compare with Pradel's assumption of incompetence], some said they used med instead of avoidance [like Prout's study] one said s/he has no choice re

Rudestam (8-12 years) **(stronger)** Focus on vulnerability/reliance on family	Koinis-Mitchell (7-10 years)	Pradel (7-12 years) Focus on age/children's knowledge/ (in)competence over experiences	Boyle (6-11 years) Concern re AA boys fear of death and extreme language	Meng (7-12 years) Concern re not avoiding triggers
				avoiding, avoid after symptoms set in or didn't seem to be aware of triggers
Emotional reaction – powerlessness and inescapability Children expressed a sense of powerlessness, a loss of personal control, in face of a inescapable external force – 'asthma will follow you around if you run around'	**Emotional reaction – Unhappiness, sense of responsibility for symptoms and awareness of danger of death** Unhappiness : 'bad' or 'sad' but also 'both good and bad' or 'in the middle' cos 'I feel confident that I can handle it' [moral framework – lack of control is a personal as well as medical 'failure']. Some children hoped them would grow out of their asthma or get better at controlling it when they got older. At least one child expresses openly that asthma may be fatal 'he could get sick and die'	**Emotional reaction – stoicism** The on-going condition did not seem to distress them though the onset of an episode was a dramatic experience - 'that night is a nightmare, it is a living.. nightmare because you are on the couch trying to breathe' and another 'I was really scared'. Children talked with a fatalism and no self-compassion and several explained it in terms of heredity, or 'born with it' or (one child) 'God's will' **Unpredictable onset** – warning symptoms not described by 7 yr olds and by few 12 yrs olds	**Emotional reaction –powerlessness and fear, including of death** Extreme language and use of upper airway language linked specifically to African-American children (major theme alongside not being able to do what you want to do, is being afraid of asthma) **Unpredictability of onset** also made it frightening	Children worried about being short of breath, dealing with seasonal triggers, being in hospital, missing school and running out of medicine. A few worried about death, medical complications, their parent's anxiety and restriction in sports/ interruption in sleep
"Growing" the same?	Some children hoped them would grow out of their asthma			
	Problems with interventions I don't like taking my meds', 'they are nasty' bad tasting. Things that make managing asthma easier include 'having to take meds less often'	Bad-tasting medicine, **tho most children also appreciated benefits: 'I like my medicines they help me out'** Side effects eg 'I feel rolling like an apple'; 'sometimes they make me feel sicker'; **Unpredictability of efficacy** - 12 yrs olds felt meds didn't always work	Taking bad-taking medicine **Unpredictability of efficacy** of interventions – even after the children took their medication they didn't know if symptoms would improve so they could resume activities	
Predominance of reactive rather than preventative treatment Most children listed reactive treatment such as emergency meds, ER, take pump		Author concerned children not familiar with 'drug category they should take for treating an asthma attack'. Only small proportion of 12 yr olds and even fewer 7 yrs olds specifically reported using quick relief medicine when having an attack tho author acknowledge they might not have realised she was expecting this distinction.		Author was concerned about over-reliance on rescue medication and felt children and parents lack of motivation for avoiding triggers was a prob [choice, compare with Pradel's assumption of incompetence] [relate to Prout's study of preference for inhaler since minimising difference]
Minimising difference **Stoicism** One girl felt her asthma did not affect her life tho her parent felt it reduced	**Forgetting:** Many children described they 'forgot' to take their medicines because they become preoccupied with other activities:	**Forgetting? Low knowledge of warning symptoms:** by 7 yr olds and by most 12 yrs olds too		**Forgetting/ignoring:** Over a quarter of children could recognise early warning

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time outside and activities.	“forgetting the pump because I am not tuned into what I am doing” – a common response. [Is a preference for a constraint-free environment in Rudestam a contrast with seeing doing well with asthma as doing what doctor/mum says – see below?] **Difference** – ‘kids staring at me’, ‘some kids laugh at me and say I’m playing’ ‘Bringing my inhaler to school and people seeing it	**Stoicism:** lack of distress about illness and discussed it with sense of fatalism and no self-compassion		symptoms though some said they sometimes denied experiencing these and one hid them from others
At school Difficult because of difficulty engaging in sports	Children felt confident at school and confident to get help from teacher [different exp from in Meng] – tho some children weren’t sure if they’re teachers ‘knew what to do’ if they got an episode and so felt more comfortable managing it at home	One boy had to get medication from office at school		Lack of access to medicines and control over self-care activities at school was a problem for the majority of children especially during gym. Some children had consulted their school nurse about their asthma symptoms and only one child lacked confidence in her knowledge
Ethnicity related observations			**See ‘emot resp section’ African American boys** expressed fear of dying from asthma and used **much stronger words** to describe their anguish than white peers; they also used **upper airway descriptors** such as not being able to breathe and it hurts to breathe **and generalised terms** like feeling hot, bad or coughing all the time. Author expresses concern that white practitioners may not to able to make correct diagnosis.	
Age differences		Author very interested in age diffs Eg 7 yr olds knowledge of warning symptoms poor and they used general/lay terms for meds, whereas 12 yr olds bio med terms.		

Appendix 13: Findings from first, aggregative attempt at synthesis

Here I set out a synthesis of findings from studies about the experiences of children with asthma and diabetes. I describe what these tell us about how children experience their illness and care across physical, emotional and psychosocial spheres; their management activities; knowledge and learning about their illness; experiences of clinical care; and what children find helpful and less helpful in managing their care.

13.1 A physical experience of illness and treatment

In line with Kelly's findings that adults' experiences of chronic illness are first and foremost of a sick and pained body (Kelly 1996; Kelly & Field 1996), children with asthma and those with diabetes vividly described the physical impact of their illness. Children with asthma were described as reporting breathing difficulties, coughing, congestion, wheezing, 'tight' or painful chest, feeling hot, nausea, sometimes vomiting and frequent illness (it was not clear if this was with asthma or minor illnesses such as colds) (Rudestam et al. 2005; Boyle et al. 2004; Dell Clark 2003; Koinis Mitchell 2003; Meng & McConnell 2002; Pradel et al. 2001; Ireland 1997; Walsh 1983):

> "I start breathing real slow and my air gets all clogged up." (Dell Clark 2003)
>
> " [it's] like having two bricks pushed together in your chest." (Ireland 1997)

Some reported that children felt these symptoms occur without warning (Boyle et al. 2004; Pradel et al. 2001; Ireland 1997) and tend to be worse in winter (Boyle et al. 2004; Meng & McConnell 2002). Children with diabetes were also described as feeling that symptoms can occur without warning (Dell Clark 2003) (my fieldwork). These included dizziness, headaches, tiredness, hunger or faintness from low blood glucose levels, or dizziness, headaches, tearfulness, irritability, hotness or thirst from high blood sugar levels (Dell Clark 2003; Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my field work):

> Sara described the symptoms of having low blood sugar as feeling her knees and hands shaking, whereas high blood sugar made her feel hyper, like "shooting a hundred basketball hoops."
> (Spezia 1991)
>
> "[When I am low] I feel very faint and I do feel very, very hungry."
> (Sutcliffe et al. 2004)

Authors of studies across the two illnesses described children to report tiredness from play and physical exercise (Rudestam et al. 2005; Zahorik 1990). Authors of studies of children with diabetes recounted how children described the discomfort of symptoms at diagnosis, such as vomiting, stomach pain, drinking a lot of water and needing to urinate frequently (Sutcliffe et al. 2004; Miller 1999) (my fieldwork) and the overwhelming nausea and loss of function associated with severe hypoglycaemia or hyperglycaemia (Sutcliffe et al. 2004) (my fieldwork):

> "Well during the night I just screamed… I was all floppy on one side and I couldn't talk - I remember actually being in there, right, saying, I wanted to have my injection, 'cos I knew that was like my routine, but like I had had a drip in my arm so I didn't need it. But I couldn't think of any words I was saying, erm 'I've gotta have my thingy'".
> (Sutcliffe et al. 2004)

Authors' described the physical experiences of children with diabetes to be dominated as much, if not more extensively, by experiences of the regimen, as by those of the illness itself (Dell Clark 2003) (my fieldwork). They reported children's longing for restricted foods (Dell Clark 2003) (my fieldwork) – for example, here 2 brothers comment on family photos of themselves at a Halloween party:

> Other photos displayed the bittersweet process of sorting the plunder Richard gained from trick-or-treating; the boys handled the candy piece by piece, picking out the non-sugar candy or pretzels or other foods permitted within their strictly controlled diet. As he sorted, Roger confessed to feeling "bad" because "when you smell it, it makes you want to eat it." His brother agreed, saying, "You want to stick your face in it and eat it." Throughout trick-or-treating, they complained, they thought about the candy they couldn't eat, rather than the money for which they would trade the candy to their parents. "You're crying 'cause you see all the candy and you want it so bad," one brother admitted. (Dell Clark 2003)

Although several researchers found children to report the pain of blood tests as less than that from injections (Dell Clark 2003) (my fieldwork), children in one study were described as getting sore fingers from the finger pricks for blood tests (Miller 1999). Children in my fieldwork study denied getting sore fingers from this, though one child pointed out how painful finger pricks can be, if the depth of the finger prick is set too high. It may be that clinicians need to ensure the children have access to finger prick equipment that they can adjust to a suitable level, and are clear about how to do this.

Authors described children's reports of the pain of injections (my fieldwork) – like 'the sting of a bee' (Dell Clark 2003). Some children said that they 'hate' injections, while others reported them as not 'that bad' (my fieldwork) or that 'after a while they don't hurt as much' (Sutcliffe et al. 2004). Likewise, some children with asthma said that they 'hated' their adrenalin injections, though others reported 'you get used to it' (Walsh 1983). Drawing on findings about how children may hide difficult experiences from adults (Bluebond-Langner 1978), one author suggested that parents were not always aware of the extent to which their child disliked injections (Dell Clark 2003). In my fieldwork study I found that adults often encourage children to bear their illness with minimum fuss and complaint. It may be that children who are stoical about their experience of injections actually find them more painful than they routinely admit. Equally, many children may find injections, especially over time, really not 'that bad' (my fieldwork).

In terms of their physical experiences of the regimen, although authors described children with asthma to appreciate the benefits of their medicines –

'your lungs come back to life' (Dell Clark 2003; Pradel et al. 2001) – they also recounted how children disliked the 'nasty' taste (Boyle et al. 2004; Dell Clark 2003; Koinis Mitchell 2003; Pradel et al. 2001). Some children also reported that medicines make them feel nauseous – '"I feel rolling like an apple."' (Pradel et al. 2001).

Children's descriptions of physical symptoms: In one study of African-American children with asthma, the author expressed concern that the upper-airway descriptors such as 'not being able to breathe' and 'not enough air' used by children in her sample are different from descriptors used by white children, and that this may lead to difficulties in diagnosis by white clinicians (Boyle et al. 2004). However, breathing difficulties was also a common description for symptoms amongst children in studies with samples mainly drawn from white populations:

> "It's difficult to breathe." (Walsh 1983)
>
> "I start breathing real slow." (Dell Clark 2003)

The author further expressed concern that African-American children's more generalised descriptions of symptoms such as 'feeling bad' might lead to difficulties in diagnosis (Boyle et al. 2004). Children, both with asthma, and diabetes, in other studies also used generalised descriptions of symptoms. For example, in my fieldwork, Marjan, aged 4, described feelings of low blood sugar simply as 'bad'; and both in my fieldwork and other work, very young children preferred to demonstrate their experiences of symptoms physically rather than giving verbal descriptions:

> Maisy was quite uninterested in talking to us about her condition, as she was only age 3 her vocabulary was somewhat limited, however, when asked by her mother to show me how she felt when her blood-sugar levels were low and she was 'wobbly' she demonstrated by holding her hands up and shaking. (Sutcliffe et al. 2004)

In her study of children with diabetes, and also in my own fieldwork, Sutcliffe and I found that children and parents are often adept at constructing narratives alongside one another (Sutcliffe et al. 2004). Boyle expresses concern that clinicians be able to understand children's generalised descriptions of symptoms, and it seems here that encouraging children and carers to work alongside one another with the clinician may be helpful. As Sutcliffe puts it:

> Parents can help interviewers by reminding and encouraging children to talk more fully about problems [for example]:
> Katherine: Can you think of any times when people haven't treated you very well and been a bit thoughtless?
> William: ...I can't really think of any.
> Mother: Only the one time when Daniel bought chocolates for him and his father.
> William: Oh yeah I went to see West Ham and I just felt left out.
> Mother: What about at school when you don't get puddings?
> William: Well I'm getting used to it now because it's happening quite a bit, but I don't mind it so much because it happens quite a lot, I'm getting used to it.
>
> (Sutcliffe et al. 2004)

Finally, Boyle reported some African-American children to use extreme terms to describe the experience of an asthma attack, for example 'like getting electrocuted' (Boyle et al. 2004). Drawing on another study with similar findings (Yoos & McMullen 1999) the author suggests that this may be either a cultural trait related to a tendency to use strong words to describe emotions, or a spontaneous association of asthma with death relating to African Americans' experiences of racism and low social status (Boyle et al. 2004). I discuss in later sections of this chapter the impact of the wider socio-economic environment on children's experiences of illness; however, no other authors of studies with ethnically diverse samples of children reported children's language use to vary by ethnicity, nor was this phenomenon one that appeared in my fieldwork.

In this section, I have described the physicality of children's experiences, in particular the physical disruption caused by the illness to children with asthma and by the regimen to children with diabetes. Next I want to look at the emotional impact of illness on children's lives.

13.2 The emotional impact of illness and treatment

Children across illnesses seemed to experience emotional disruption as a result of fear of the sudden onset of symptoms, and, sometimes, in relation to morbidity or mortality. Authors in two studies, one with children with diabetes and one with children with asthma, reported children as feeling the burden of their illness as inescapable:

> "Asthma will follow you if you run around." (Rudestam et al. 2005)
>
> … another implied that the diabetes is a load that you cannot escape from when stating "if I went to Australia I'd have to bring it." (Miller 1999)

Children with asthma were reported to feel anxiety (Meng & McConnell 2002), sadness (Pradel et al. 2001), powerlessness (Rudestam et al. 2005) and fear (Boyle et al. 2004; Dell Clark 2003; Pradel et al. 2001) - including fear of dying (Boyle et al. 2004; Dell Clark 2003; Koinis Mitchell 2003; Walsh 1983). Descriptions of children's expressions of fear were most extensive in Dell Clark's study, which was the only one to use a sample entirely comprised of children with a diagnosis of severe asthma:

> Scared was a word children used often in describing the feeling of asthma. For example, one child described asthma as a 'scary' experience, analogous to having a "bad guy" nearby. Another youngster said that in a place analogous to asthma, you had to say "bye-bye life." Asthma has an ominous association, as an experience "far from air" in which you "worry you might die."'
>
> (Dell Clark 2003)

Much of Dell Clark's data focused on children's emotional experiences of their illness. I have already described how, drawing on findings about how children may hide difficult experiences from adults (Bluebond-Langner 1978), she suggested that parents were not always aware of the extent to which their child disliked injections (Dell Clark 2003). She also proposed that children with asthma routinely hide their fears about the illness because of an awareness of adult discomfort around this (Dell Clark 2003).

Rudestam found a spatial aspect to children's emotional experiences of their illness: that their knowledge of asthma triggers made them feel vulnerable in places where triggers are more commonly found, and safer in places free from asthma triggers (Rudestam et al. 2005):

> Children with asthma said that certain places felt unsafe or uncomfortable because they triggered their asthma, even before being questioned about their illness. For example, one boy said "[I wouldn't want to be in the bedroom] because there could be dust and stuff in there." A 12-year-old girl said she feels safest at home because other places triggered her asthma: "Because my aunt has cats, and my friend has a golden retriever..." (Rudestam et al. 2005)

Some authors reported children with diabetes to convey unease about the potential for the sudden onset of low blood sugar levels (Spezia 1991); (Sutcliffe et al. 2004), particularly at night (Dell Clark 2003):

> A severe [hypoglycaemic] reaction with changed consciousness and physical symptoms can make a child uneasy or frightened... Lows can be treated, but they nevertheless leave behind traces of a basic unsteadiness. (Dell Clark 2003)
>
> "Well it's quite worrying because you might have a hypo, so I worry about that." (Sutcliffe et al. 2004)

Children's comments about the onset of high blood sugar showed awareness of the potentially fatal nature of hyperglycaemia (Sutcliffe et al. 2004). However, these were usually qualified with a statement about failure to implement the proper interventions (Sutcliffe et al. 2004; Zahorik 1990):

> Children did mention other people had died from diabetes but attached a statement of qualification such as "He didn't take care of himself". (Zahorik 1990)
>
> "But it's quite difficult to remember your injections, and if you forget them you might die. My father told me about a kid who forgot her injections for a week and she died, so try to remember."
> (Sutcliffe et al. 2004)

In contrast, in 2 studies, children with asthma were reported as raising concerns that their medicines are not always effective (Boyle et al. 2004; Pradel et al. 2001):

> Even after the children took their medication there was a sense of waiting, of not knowing if the symptoms would improve so they could resume their activities. (Boyle et al. 2004)

In my fieldwork, some children with diabetes expressed misunderstandings about potential long-term health problems and nervousness about discussing these with adults. Children with diabetes in other studies were also reported to be aware of, and worried by, potential morbidity arising from their illness (Miller 1999; Zahorik 1990) (my fieldwork):

> Knowing that you might have more health problems when you are grown up can cause you to worry. (Miller 1999)

Although, once again, one author reported anxiety about this to be alleviated by confidence in their ability to manage the illness well (Zahorik 1990). It seems that though the anxieties of children with diabetes may to some extent be mitigated by confidence in the effectiveness of the regimen, children with asthma may not have the same faith that interventions will protect them from harm.

Children across illnesses also seemed to experience emotional disruption as a result of the regimen, as well as arising directly from the illness itself. Much of this seemed to be of a psychosocial nature, and is discussed under that title in the next section. However, outside of social experiences, children with asthma were reported as feeling sad about not having, or having had to give up, pets (Boyle et al. 2004; Dell Clark 2003; Walsh 1983):

> Sean had given up a dog, Petticoat, two years earlier. He had felt deeply attached to Petticoat... "I want Petticoat. I miss Petticoat. Can we get Petticoat back?" Sean had pleaded. But Mrs. Benson could not watch her children wheeze. She saw to it that her family could visit Petticoat at the dog's new home, which they still visited annually. Some visits had been tearful, since Petticoat clearly still recognized Sean and his family... Sean recalled with nostalgia how he had shared fun and confidences with his canine "best friend".
> (Dell Clark 2003)

Meng found, though did not describe in detail, how children with asthma were also anxious about going to hospital, running out of medicines and missing school (Meng & McConnell 2002). Another study of children with asthma found children did not mind missing school per se, but worried about having to "catch up" on work they had missed (Boyle et al. 2004). Some children with asthma were reported to say that feeling sad makes it even harder for them to remember their medicines, while others were described as reporting that "feeling bad makes me more careful" (Koinis Mitchell 2003).

Children with diabetes were described as expressing sadness and frustration about dietary restrictions and having to have injections - although as I have already reported in the previous section, individual feelings about injections seemed differ for different children (Dell Clark 2003; Miller 1999; Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990)(my fieldwork).

> Dietary restrictions prevent you from eating what you want, when you want it, which is very frustrating. (Miller 1999)
>
> Whether or not parents were aware of it, children with diabetes harbored dislike toward injections, although the dislike was not necessarily proclaimed to all. In private interviews, children said that shots engendered a combination of dread, anger, hurt, or fear. "Having to take injections" was a pronounced dislike... Shots cause pain, not only on a physical level but also on an emotional, expressive level. However sterile and efficiently delivered, injections do violence to the boundaries of self. (Dell Clark 2003)

Several authors reported that pain and fear during clinical treatment for high blood glucose levels, including diagnosis, rendered some children afraid of finger pricks or needles - thus making future daily management, or clinical treatment, such as the annual blood test, especially stressful for them (Sutcliffe et al. 2004) (my fieldwork):

> Having a butterfly needle put in [at diagnosis] is one of the most painful things that children described that they experienced... for Edwina this was the beginning of "needles forever", but this introduction was far worse than the needles she has to have daily... The beginning need not be so oppressive and frightening.
> (Sutcliffe et al. 2004)
>
> Interviewer: And can you remember the first time you did a blood test? Did somebody else do that for you?
> John: Yeah, they just pricked it, they didn't have one of those things with a needle that pricks it [the hospitals use disposable finger prickers which... have much larger needles in], and I thought, 'Oh God I'll have to do this for the rest of my life.' The pen prickers [used at home] aren't too bad. (Sutcliffe et al. 2004)

It was clear from observations carried out as part of my fieldwork that some children with diabetes also experienced stress as a result of adult enforcement of the regimen, for example, in the previous chapter on findings from the fieldwork, I described Spiderman's confrontations with his mother about access to restricted foods.

Finally, authors described children across the two illnesses engaged in on-going internal processes related to taking responsibility for management, which I would argue are unlikely to be sustainable without some kind of personal, emotional impact. For example, children were described as engaged in private deliberations about whether or not to follow the imperatives of the regimen (Miller 1999) (my fieldwork); 'paying attention' to the illness, in terms of planning ahead to minimise potential problems (Ireland 1997); and 'constant vigilance' of (Zahorik 1990) their physical state and the possible onset of symptoms:

> "When we get to choosing stuff, they're all gobbling away, and I say, shall I eat it, or shall I not?" (Miller 1999)

> Diabetic children must maintain a constant vigilance in regards to symptom awareness, as opposed to healthy children who may not have the continuous and urgent need to interpret bodily sensations. After recognition of a state of ill health, a decision must be made regarding appropriate action. (Zahorik 1990)

> The category "paying attention" incorporated children's deliberate problem-solving efforts [including] planning activities and therapy to minimise the risk of a potential asthma attack. (Ireland 1997)

In this section I have described how children across both illnesses seemed to experience emotional disruption as a result of the sudden onset of symptoms, knowledge about mortality, the regimen and their responsibilities for care. In the next section I describe further emotional disruption of a psychosocial nature.

13.3 The psychosocial impact of children's illness and treatment

Children across illnesses seemed to experience psychosocial disruption as a result of their illness or regimen. Children with asthma were described as reporting that their illness limited their physical activity (Rudestam et al. 2005; Boyle et al. 2004; Koinis Mitchell 2003; Pradel et al. 2001; Walsh 1983), time spent outside (Rudestam et al. 2005; Pradel et al. 2001;), and hence, time spent with friends (Rudestam et al. 2005):

> "When my asthma's bad, my mom won't let me go out and play with friends, and I feel bad, but she won't let me go outside."
> (Rudestam et al. 2005)

> "My friends say 'let's run,' and I can't." (Walsh 1983)

Boyle felt that participation in sport was a particularly important and valued activity for the children in her sample, who were mainly from an African-American background. She described how both boys and girls talked about how much they liked sports and how the classrooms and corridors of their school were decorated with pictures of high profile sports figures. Boyle recounted how the children all knew about one particular athlete who suffered from asthma but was still an outstanding sportswoman. She implies that the limitations which asthma places on their involvement in sport may be particularly frustrating for these children (Boyle et al. 2004).

Some children with diabetes were reported as describing their illness as interrupting their ability to do school work (Zahorik 1990) (my fieldwork study). Children across illnesses were reported to find their regimen, as well as their illness, to cause limitation and interruption in their lives. Children with severe asthma, who had to use a nebuliser or 'breathing machine', were described as feeling frustrated by the prolonged periods of time involved in receiving treatment from this (Dell Clark 2003) – "I feel like I'm locked up in a cage." There also seemed to be an age-related aspect to children's experiences of disruption from the regimen, in that Pradel found that while 7 year-olds with asthma described regular medicine-taking as disrupting and time-consuming, 12 year-olds did not (Pradel et al. 2001). The author did not explore this in any greater detail but it may be that this is related to the fact that younger children's use of medications tends to involve adult supervision, and hence a greater interruption while this is sought, whereas older children tend to take medicines more autonomously, and hence, perhaps, with less interruption.

Children with diabetes were reported to experience the regimen as restrictive, inescapable, boring, time consuming and intrusive (Dell Clark 2003) (Miller 1999) (my fieldwork):

> Certain tasks, which take time, must be done each day, and this gets boring... the need to do things on time can be very irritating... diabetes is forever and you are not allowed to forget it. (Miller 1999)

They were described as disliking the interruption caused by the relentless regimen of injections and tests and having to have regular meals and snacks (Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork):

> "[I don't like] shots and getting tested every morning... eating breakfast at 8.00 instead of 9.00, eating snacks at 10.00, lunch two hours later, snack again two hours later, dinner, snacks..."
> (Zahorik 1990)

> Interviewer: Are there any not so good things, the worst thing, about having
> diabetes?
> Edwina: Injections.
> Interviewer: Is it that they hurt?
> Edwina: Doesn't hurt. Sometimes I can't be bothered.
> Interviewer: The nuisance?
> Edwina: Yes, I could be in the middle of something fun, and my mother goes, "It's time to do that thing". Gets on my nerves.
> (Sutcliffe et al. 2004)

Children were also described as disliking the limitation imposed on sleepovers by the necessity of having insulin injections – specifically that they could not stay overnight at friends' houses until they had learned to do their own injections (Zahorik 1990) (my fieldwork). Children were described as feeling sad about the restrictions of the diabetes diet and how it meant that they could not have certain foods; and that they found it particularly painful that others could enjoy these treats when they could not (Dell Clark 2003; Miller 1999; Spezia 1991; Zahorik 1990) (my fieldwork):

> "I feel sad [seeing a picture of a cake] 'cos I usually won't get the frosting and a lot of people would." (Dell Clark 2003)

> "I don't like it because I can't eat stuff that other kids have."
> (Spezia 1991)

In my fieldwork, I suggested that that the disruption caused by the regimen may be compounded when it restricts participation in activities important to maintaining ethnic identity – for example, when the diabetes diet prevents a child's participation in traditional family meals.

Some children across the two illnesses were described as disliking having to carry out care activities in front of others; for example, for children with diabetes, having snacks in front of peers (Zahorik 1990) (my fieldwork); and for children with asthma, embarrassment about using their inhalers in front of others (Dell Clark 2003; Koinis Mitchell 2003):

> A child commented, "If I need to eat (in school) it bothers me. People ask questions." Another child said the first day of school always makes her sad, "I get embarrassed on the first day of school. I have to eat a snack and people look at me like "Are you sick?" and then I have to pass up other [student or school-provided] snacks. I say, "Just skip me," then they say, "Why, don't you like it?" and I say, "Yes, but just skip me." (Zahorik 1990)
>
> ""It's not nice to watch someone take their medication. The teacher told them not to look at me when I take my medication ... I don't like to do it in front of a lot of people, that would be embarrassing."
> (Dell Clark 2003)

Equally, some children with diabetes were described as enjoying being able to have food when others are not (Miller 1999; Sutcliffe et al. 2004):

> "I like, I like [pause], I like about diabetes 'cos I like diabetes, because every time, when I get a biscuit, my sisters say 'ohhhh!'"
> (Sutcliffe et al. 2004)
>
> Being diabetic allows you to enjoy special treats which makes others jealous. (Miller 1999)

Some children across the two illnesses were described as having experienced teasing or bullying by peers or siblings about their illness (Sutcliffe et al. 2004; Koinis Mitchell 2003; Miller 1999; Zahorik 1990; Walsh 1983) (my fieldwork), or having experienced peer concern that their illness is contagious (Spezia 1991; Walsh 1983):

> One of the most problematic consequences attributed to having asthma was that of being teased by other children. Some children mentioned this when speaking of physical activities such as running... "Well, they just tease me 'cause I can't run very fast." For others it was a much more personal and internalized experience... "They start teasing me and calling me 'asthma buttons'" ... "Sometimes people tease me . . . she calls me 'wheezer' ... one day I had an asthma attack in school, and she says, 'sad' [sarcastically], and that is sad!" (Walsh 1983)

Yet children were also described as reporting peers and siblings, as well as parents and teachers, as supportive and helpful; for example, in recognising when they are low, or having an attack, and helping them with this, or simply by providing emotional support (Miller 1999; Nabors et al. 2003; Pradel et al. 2001; Sutcliffe et al. 2004; Spezia 1991; Zahorik 1990)(my fieldwork):

> "[Managing asthma is easier now] because I have more friends and they care about me." (Koinis Mitchell 2003)
>
> "Everybody knows. My friends… if I look pale or something, they'll go get the teacher." (Spezia 1991)

Some children with diabetes were described as requesting more support from friends in terms of reminders about sticking to their regimen – also walking them to the nurse when they are low, and not eating junk food in front of them; though others were reported to consider regular reminders too intrusive (Nabors et al. 2003). Some children were reported to say that they preferred not to talk about their illness at school because they did not know how, or want, to answer peers' questions about it (Sutcliffe et al. 2004; Walsh 1983) or because no one was interested:

> "It bugs me a lot because they ask too many questions and I try to answer 'em best I can but sometimes I can't answer them." (Walsh 1983)
>
> George added that he kept trying to explain to friends at school, but it was boring to keep repeating the points and they weren't interested, so he doesn't bother. (Sutcliffe et al. 2004)

However, children across both illnesses were reported as sometimes finding enjoyable the extra attention arising out of their illness – even though it doesn't outweigh the negatives of having the illness (Miller 1999; Walsh 1983; Zahorik 1990):

> "They treat you nice and I always get coming-home presents from my dad." (Walsh 1983)
>
> The extra attention received because you are diabetic makes you feel special, which is a nice feeling. (Miller 1999)

Although, sometimes even well-intentioned attention could feel uncomfortable:

> "Everyone was treating me too nice. I felt like a baby. I thought they were spoiling me." (Walsh 1983)

Some authors described children with asthma as feeling isolated by their illness and different from others (Walsh 1983) – especially during the onset of symptoms (Ireland 1997). Some reported that they are treated differently by others because of their illness: that teachers tend to be over-cautious in restricting their involvement in physical activities (Boyle et al. 2004; Walsh 1983), and peers tend to underestimate their capabilities (Walsh 1983):

> "I'm good at pretty many sports, but people haven't let me show them how well I can do it, so they still think, oh, she's no good at all those things." (Walsh 1983)

Children with diabetes seemed to be ambivalent about the extent to which they are different from others as a result of their illness. Some were described as stating that it is only the diabetes regimen that sets them apart (Spezia 1991) (Zahorik 1990). Yet one child reported "when I'm feeling quite annoyed and stuff like that, I feel that I'm different" (Sutcliffe et al. 2004); and Sutcliffe described detecting some defensiveness around this (Sutcliffe et al. 2004):

> Some children seemed defiantly positive, aiming to show the world, and other young people with diabetes, that they are able to avoid diabetes limiting their life. But the way these messages are given suggests they feel that having diabetes means they have to protect their liberties to a certain extent. They want to show people that it doesn't make them different. This was also shown when we asked children if they felt more or less the same as their friends. The overwhelming message from the children was 'Yes', and it was often said with a sense of resentment that we should ask such a question. We got the feeling from many children that they wanted to protect and promote their sameness, their normalness. (Sutcliffe et al. 2004)

This chimes with findings from work which identified children across both illnesses as placing a very high priority on maintaining their normality in relation to peers or their pre-illness lives (Miller 1999); (Ireland 1997)

(Walsh 1983) (my fieldwork study), and which I will discuss further in the section on what children find helpful in managing their illness.

In this section I have described the disruption children seem to experience on a psychosocial level: children with asthma particularly as a result of the onset of symptoms, and children with diabetes particularly as a result of the intense regimen. In the next section I describe children's management of their illness.

13.4 Children's management of their illness

Some children with diabetes, even from 4 years or 6 years, were reported as doing their own injections with some regularity (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork).

> The high level of skill amongst these children is perhaps best exemplified by the ability of some of the younger ones. For example, Nicola at 4 years and DJ at 6 years took on the role of doing their own blood tests and injections... From 4 years of age, when Nicola went to stay away from her family with relatives, she would explain and show them what she had to do. (Sutcliffe et al. 2004)

Many were described as continuing to need help reaching certain injection sites or ensuring rotation of sites, and to prefer an adult to do injections at rushed times, such as in the mornings before school (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990)(my fieldwork):

> Of the 26 children in this study, 15 (57.7%.) claimed to be self-injectors. Most of these children (n=13) ranged from 9 to 12 years old. In addition, two 8 year-olds claimed to have prime responsibility, but needed help when rotation of injection sites necessitated shots in hard to reach areas, such as an arm or the "behind." (Zahorik 1990)

Children from 4 or 5 years were described as reporting that they do their own blood tests on a regular basis (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork), though children were also described as sometimes wanting carers to do their blood tests long after they were capable of doing them themselves, or splitting this task with carers so that the child pricked their own finger and carers took responsibility for waiting to check the meter reading, as this reduces interruption into the child's activities (Spezia 1991) (my fieldwork):

> "I just check my blood and that takes a minute, which my mom just pricks my finger and I wipe off my finger from blood. I just go ahead and play and she is already doing it for me. So, I can do my own stuff that I have to get done." (Spezia 1991)

Zahorik's study was carried out at a time when some children were still regularly relying on urine tests to check blood glucose, though most were described as preferring to use blood tests:

> Reasons given for preferring blood tests were convenience… the ease of process… "Sometimes I don't have to go to the bathroom, but I can always bleed!" … and avoiding an unpleasant social situation: "...company comes and friends see you going to the bathroom in a cup...with blood (tests) you can get it over with"... The children also recognized increased accuracy in blood testing. (Zahorik 1990)

Most children - across ages – were described as readily identifying healthy food options appropriate to the diabetes diet, and presenting themselves as making good decisions about food choices (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork):

> Yet young children could be reliable about restricting the number of 'treats' that they ate, such as Emma aged 5 years, deciding how many sweet things to eat at a party. When aged only 4 years, on one occasion, while they were away from adult supervision, although her friend ate lots of chocolates Emma said that she did not join in this secret treat, and her low blood sugar levels confirmed her words. (Sutcliffe et al. 2004)

Children with asthma were described as using a range of techniques to manage their illness, including resting, relaxing, breathing exercises, restricting physical activity, drinking water, moving away from pets, going into an air-conditioned room, taking medicines and going to hospital – and sometimes described as using these in a hierarchical approach to management, whereby relaxation or breathing exercises are implemented prior to use of medicines (Dell Clark 2003; Ireland 1997; Koinis Mitchell 2003; Pradel et al. 2001; Rudestam et al. 2005; Walsh 1983):

> Often breathing exercises were the first technique used in a sequence of actions. For example: "I do my breathing exercises, then if breathing exercises don't help, I get Alupent, and if that doesn't work, I go to the hospital." (Walsh 1983)

Some authors found more older children (approximately 10-12 years) to take medicines independent of adult supervision than younger children (approximately 6-8 years) (Boyle et al. 2004; Pradel et al. 2001); and 12 year-olds to use a wider range of management techniques than 7 year-old children (Pradel et al. 2001):

> Children's behavioural responses to symptoms experienced differed by age group. Younger children mostly took some rest, told their mother, or did not know what to do. On the other hand, older children used a variety of asthma management strategies other than taking medicines, such as relaxation, breathing techniques, or resting. Like younger children they also told their mother they were not feeling well... For most young children the decision to take asthma medicines was made by their caretaker. Over half of older children reported taking asthma medicine on their own when experiencing the asthma episode... Older children show more autonomous behaviour in managing their asthma than younger children. (Pradel et al. 2001)

This fits with Walsh's finding that children who initiate management techniques independently tend to use a wider range of approaches than children who turn to others for help (Walsh 1983) – 'The 41 self managers used an average of 2.3 techniques per child. In comparison to the other managers who used 1.3 techniques per child. Thus, the self managers considered more options' (Walsh 1983). This contrasts with the findings with children with diabetes where independent management did not seem to be linked to age, but to other factors such as children's desire to share care with adults in order to save time.

Finally, as I have already described, authors found children across the two illnesses to demonstrate on-going responsibility and decision-making about their illness and management (Zahorik 1990), including private deliberations about whether or not to follow the imperatives of the regimen (Miller 1999) (my fieldwork); 'paying attention' to the illness by planning ahead to minimise potential problems (Ireland 1997); and 'constant vigilance' of (Zahorik 1990) their physical state and the possible onset of symptoms. Zahorik's idea of 'constant vigilance' chimes with Ireland's description of how children with asthma learn to 'appraise the severity of the asthma ... [and put in place] personal baselines against which the effects and consequences of having asthma could be measured' (Ireland 1997).

Lack of concordance: As I described in an earlier chapter, Sanz has recommended use of the term 'concordance' to refer to the achievement of harmony between patient and practitioner agendas – as opposed to the term 'compliance' which implies a more hierarchical relationship between patient and practitioner (Sanz 2003). Here I describe examples of children and practitioners holding divergent agendas about managing care. Several asthma studies found children to favour responsive over practitioner recommended preventative approaches to management (Meng & McConnell 2002; Pradel et al. 2001; Rudestam et al. 2005):

> When children were asked what kind of things they did to make their asthma feel better, 13 listed reactive (eg emergency medication, emergency room treatment, cessation of activities), rather than proactive treatments (eg controller medication that is used to reduce likelihood of asthma episodes). Common responses were, 'I lay down', 'take my pump', 'drink water' and 'go to the hospital'.
> (Rudestam et al. 2005)

> Presence of symptoms guided children's decisions to use medication and was the driving force in seeking parental help.
> (Meng & McConnell 2002)

- and that few children used the peak flow meter, an instrument intended to objectively assess respiratory health outside of the subjective experience of symptoms (Dell Clark 2003; Meng & McConnell 2002; Pradel et al. 2001).

Children with diabetes were sometimes described as reinterpreting their regimen to fit in with their own needs and desires, in that rather than aiming for balanced blood glucose levels at testing, they hoped for a 'low' so that they could have something to eat (Sutcliffe et al. 2004)(my fieldwork):

> When asked, 'What happens when you get low blood sugar, what do you feel like?' Guy Fawkes... replied:
> Guy: Happy! [mother laughs in background]
> Interviewer: Why do you feel happy when you have low blood sugar?
> Guy: I can eat things sometimes!
> He goes on to talk about sweet things. (Sutcliffe et al. 2004)

Children across both illnesses were reported as saying that sometimes they 'forget' (perhaps, sometimes, purposely) to take their medicines when they are preoccupied with other activities; children with diabetes were described as sometimes 'cheating' on their diet; and children with asthma as sometimes ignoring early warning symptoms or triggers (Ireland 1997; Koinis Mitchell 2003; Meng & McConnell 2002; Pradel et al. 2001; Walsh 1983; Zahorik 1990) (my fieldwork):

> Many children also mentioned that they "forget" to take their medicines as prescribed by their doctor and tend to become "preoccupied" with other activities such as socializing with friends and "forgetting the pump because I am not tuned into what I am doing," which was a common response. (Koinis Mitchell 2003)
>
> One child explained that his blood sugar was high that day because he "cheated on his diet" at a school carnival. (Zahorik 1990)
>
> The children who said they use [the denial] technique claim that they can continue with their activities despite increased wheezing. For example, in response to "what happens when you start wheezing?" one child replied, "It doesn't mean anything, I just keep going."
> (Walsh 1983)
>
> Older children and younger children to a lesser extent, knew what precipitates their asthma episodes. However, they did not mention any attempt to avoid these allergens. (Pradel et al. 2001)

I will discuss further the opposing views of authors about the reasons for children's departures from the regimen in the following two sections – first, on children's knowledge and understanding of their illness, secondly in the section on what children find helpful in managing their illness.

13.5 Children's knowledge/understanding about their illness and care

Authors of studies with children with diabetes and those of studies with children with asthma reported that when asked about the causes of their illness, children tended to say that they did not know (Walsh 1983; Zahorik 1990); alternatively some indicated the role of heredity (Sutcliffe et al. 2004; Pradel et al. 2001; Zahorik 1990; Walsh 1983), or physical malfunction (Zahorik 1990). A few children with diabetes were described as believing their illness to be caused by their dietary choices (Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork):

> When the children were asked "how come you have asthma?" ... the most frequent reasons given were "I don't know, I just do" (n=12; 20%) and statements indicating a belief in the role of heredity (n=12; 20%). In addition to those who directly stated "I inherited it," these responses included "because it's in my genes," "because my mom [or dad] had it," and "I was born with it." (Walsh 1983)
>
> When asked what caused their diabetes, many of the children (n=11, 42.3%) simply stated that they did not know... [other responses] included some form of body malfunction (n=5, 19.2%) such as, "It's just when the pancreas doesn't work." ... eating too much sugar or starch (n=3, 11.5%), followed by germs or viral agents (n=2, 7.7%), and heredity (n=2, 7.7%). (Zahorik 1990)

Authors of studies across illnesses also suggested that children understood their illness in terms of their own personal experiences of symptoms and care (Dell Clark 2003; Rudestam et al. 2005; Sutcliffe et al. 2004; Walsh 1983; Zahorik 1990)(my fieldwork); for example, diabetes understood in terms of injections, food and exercise regulation, and asthma in terms of not being able to breathe, or having to limit physical activity:

> When I have an asthma attack and [friends] say, "oh, what's asthma?" I say "It's difficult to breathe and something frightening".
> (Walsh 1983)

> Children either reported they did not know what asthma was, or gave explanations based on their personal experiences. Many emphasized disruptions and limitations of activities, as well as the need for acute medical care. For example, children said that asthma meant: 'You can't breathe that much and when you play you get tired', 'You have to take certain medicines' and 'They give you an inhaler and if you get an attack you go to the hospital'. (Rudestam et al. 2005)

> The child's definition… reflects ordinary, day-to-day activities. What is diabetes? "I don't know, it's just you get shots all the time" (boy, eight). "It's a disease that means you can't eat sugar" (girl, seven). "It's where you get shots, and you do blood in your finger" (girl, seven). "It's just you can't have much sugar, and you have to do blood tests and shots" (boy, seven). (Dell Clark 2003)

A particularly interesting example of this was raised by Zahorik who described several children using the terms 'sugars' to describe their diabetes: the illness defined in terms of its restriction on the child's diet (Zahorik 1990).

Accordingly, authors described children's knowledge, in relation to their own social and physical experiences, as strong. Children with diabetes, some from 3 years old, were reported to recognise the symptoms of hypoglycaemia – though to be less confident recognising hyperglycaemia (Spezia 1991)(my fieldwork) - and as knowing how to respond to these (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork):

> Interviewer: And what's a hypo?
> Simba: Cos when I don't eat all my food, I go to bed. And in middle of the night I start feeling shaky. I always look at the wall, like that [demonstrates] and stay like that.
> Interviewer: And what do you do then?
> Simba: I say, 'Help!'… Cos I thought I was getting sucked down a hole. [My mother gives me] Hypo stop, sort of jelly thing and she gives me chocolate and last time she gave me mini roll.
> (Sutcliffe et al. 2004)

As described in the previous section, children were reported to show expertise about how to do injections and blood tests, and to have a good knowledge of the timetable for these (Dell Clark 2003; Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork); and a study with older children with diabetes (9-12 years) also found some children to know their insulin doses and the types of insulin used (Spezia 1991). Likewise, children with asthma were described as knowing the times of day when they were supposed to take their medicines (Walsh 1983), and being able to identify what triggers their asthma (Dell Clark 2003; Meng & McConnell 2002), including: physical activity, pollen, smoke, dust, dirt, pets, weather (Rudestam et al. 2005; Boyle et al. 2004; Pradel et al. 2001; Walsh 1983), though Pradel reported that 12 year-old children identified a more comprehensive list than 7 year-olds (Pradel et al. 2001):

> Besides physical activity, environmental triggers (outdoor temperature, changes in the weather, pets, dust mites, pollens, dust, smoke) and other illness were mentioned by children as causing their asthma episode. Overall, older children gave a more comprehensive list of environmental triggers than younger children.
> (Pradel et al. 2001)

On the whole, children's knowledge of abstract, biomedical models was described as less strong than that relating to their day-to-day experiences (Dell Clark 2003; Walsh 1983; Zahorik 1990) (my fieldwork):

> ...less than one-half of the children could correctly draw the lungs.
> (Walsh 1983)

> While diabetic children are necessarily involved in management tasks, they do not always indicate that they understand the underlying pathophysiology that necessitates these actions. (Zahorik 1990)

However, in the report of my fieldwork I recounted how Christensen (Christensen 2000) has described children as beginning to learn bio-medical models of illness by making links between these and their experiential understandings. I found regular examples of when children made the link between the physical experience of hypoglycaemia and an abstract understanding of this as a low level of blood glucose in my fieldwork, and as I have already described, other studies which considered the competencies of children with diabetes also found children able to make this link, including some from an early age (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990). Further, data showed evidence of children beginning draw on abstract, bio-medical models of their illness, and terms relating to these, such as 'lungs' or 'pancreas' in their descriptions of their illness or the function of their medicines (Sutcliffe et al. 2004; Walsh 1983; Zahorik 1990) (my fieldwork). Several authors noted that it was older children, or those with more severe illness that used these terms:

> Although some younger children used bio-medical terms, more than half of them only employed general or lay terms when referring to asthma medicines and devices. This contrasted with older children who mostly used biomedical terminology. (Pradel et al. 2001)
>
> An eight-year-old boy, one of the oldest children interviewed, had begun to internalize the biomedical model of asthma and was able to identify and explain the role of the lungs and bronchial tubes when shown a medical drawing, unlike other children shown the same drawing. This child with severe asthma... might have been a poster child for scientific patient education had he not been so exceptional, contrasting with how most children interviewed understood asthma. (Dell Clark 2003)

- although in her observations of children at asthma camp, Dell Clark notes that understandings of illness in terms of interventions, rather than bio-medical theory, still dominate older children's understandings:

> Even at the advanced age of ten and eleven, girls studied through participant observation at asthma camp tended to place salient emphasis on treatment devices for asthma, rather than on bodily organs or biomedical theory. For instance, the campers jointly invented an imaginary toy on the last day of camp, an "Asthma Barbie" doll, accessorized with an inhaler, nebulizer, and oxygen mask. Asthma Barbie would come with toy paraphernalia of treatment - her defining characteristic. (Dell Clark 2003)

Likewise, children, especially younger children (about 6 - 7 years) were reported to identify intervention equipment and medications by their outward physical characteristics, such shape or colour (Boyle et al. 2004; Pradel et al. 2001) (my fieldwork), rather than knowing the technical names for medicines (Walsh 1983)

> While medications were reported as the most frequently used management technique, the children's knowledge of medication was minimal. Twenty-four (39%) of the children, 13 girls and 11 boys, knew the correct name of one or more of the medications which were prescribed for treatment of their asthma. (Walsh 1983)

> Particularly memorable to the younger children was the color of the medication, with many of them volunteering that they took the yellow, gray, purple or blue medicine. (Boyle et al. 2004)

One author expressed concern that children could not differentiate between preventative and quick-relief medicines and suggested that packaging for these are standardised by colour in order to help children differentiate between them (Pradel et al. 2001).

Several authors described children's learning as based on the accrual of experiences over time (Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork):

> Like many adult interviewees, George clearly remembered the incidents in hospital when he was diagnosed 2 years earlier, but not the detailed information. Like others he also found it hard to be certain when he learnt new knowledge; as his mother had diabetes, he already knew quite a lot. Families learn so much through daily experience and trial and error that the reference at the end about 'picking up' information is highly relevant to their learning methods...
> Mother: You knew the basics didn't you? [because she has diabetes]
> George: And some of the advanced bits.
> Mother: But he's picked it up quite a lot since, inn't ya?
> (Sutcliffe et al. 2004)

Drawing on models from developmental psychology, others related children's capabilities to chronological age, though this, also, occasionally, via their accumulation of experiences (Meng & McConnell 2002; Pradel et al. 2001):

> The abilities of the children were those expected of concrete operational school-age children. Since understanding is oriented toward actual observation of concrete events in the child's environment and that knowledge is constructed through physical action and experience (Piaget. 1960), it is not surprising that greater severity [of illness] was associated with greater knowledge.
> (Walsh 1983)

> In the preoperational stage (2 to < 7 years), children's explanations are directly related to their perceptions of their experiences and environment and they begin to engage in social behaviour. During the concrete operations stage (7 to < 12 years, children gain ability to solve concrete problems, they differentiate between self and others, they develop an understanding of causal relationships and their behaviour becomes more autonomous. (Pradel et al. 2001)

Sutcliffe argued that this last approach underestimates the competencies of children, and that the capabilities of some children with diabetes in her study exceeded those of their 'age/stage' (Sutcliffe et al. 2004). This is also borne out by some data in this review; for example, as already described, some children younger than 7 years, across both illnesses, were reported to show good understandings of causal relationships, for example, between asthma triggers and getting asthma (Dell Clark 2003); and of problem solving, for example, choosing appropriate foods in relation to the diabetes diet (Sutcliffe et al. 2004) (my fieldwork). However, only those authors using play-based methods incorporated children under 6 years in their samples (Sutcliffe et al. 2004; Dell Clark 2003;) (my fieldwork). Sutcliffe makes the point that it may be that worries about effective communication with younger children discourage other researchers from including younger children in their research and that this in turn perpetuates under-estimation of younger children's competencies (Sutcliffe et al. 2004).

It was only authors using the 'age/stage' model who suggested children's lack of understanding as explanations for children's departures from the regimen. Meng suggested that younger children (approximately 7 or 8 years old) may not be 'developmentally capable' of understanding that early warning symptoms, left untreated, will lead to worsening symptoms (Meng & McConnell 2002). Pradel expressed concern that children's knowledge of early warning signs is poor, in particular that of 7 year-olds. She suggested that perhaps younger children do not routinely experience early warning symptoms (Pradel et al. 2001). By contrast, authors who expressed belief in the importance of direct experience in children's learning tended to emphasise children's competencies and good understandings of their illness and care, rather than short-comings:

> A child might use lay terminology, referring to a finger-sticking lancet used to check blood as a "pin" or "poker," but the treatment procedures and diet restrictions were all too familiar. Conversant about how to use syringes and the strips used in blood-glucose testing, children were experts in their own treatment.
> (Dell Clark 2003)

> The children displayed commendable levels of competence... Indeed one diabetes nurse specialist conceded that she was sure that the children she saw were capable of more than people gave them credit for. (Sutcliffe et al. 2004)

I shall return to discuss this difference in perspectives in the next section on what children find helpful in managing their care, below. Finally, both authors using an 'age/stage' model and those focusing on the accrual of experiences over time conclude that the continuous nature of children's learning renders vital the on-going provision of good information and education for children about their illness and care (Pradel et al. 2001; Sutcliffe et al. 2004).

13.7 What is helpful in managing illness and care?

In this section I discuss what children reported to find helpful in managing their illness and care, and this includes an alternative explanation to children's lack of understanding as the reason for departures from the regimen. Some children with asthma reported hoping that they would grow out of their illness, or that it would at least improve as they got older (Dell Clark 2003; Koinis Mitchell 2003; Walsh 1983). Others found their confidence to manage their asthma improved over time (Koinis Mitchell 2003). Children with diabetes reported that with the passage of time the regimen can become so much a part of you that 'the extra things you need to do are not even noticed' (Miller 1999). Over and above issues related to the passing of time, the following factors were reported as important to children in managing their illness.

The importance of maintaining normality: As I described earlier, children across illnesses were described as reporting variations in the degree to which their illness made them feel different from others (if at all), and one author detected a degree of defensiveness around this (Sutcliffe et al. 2004); in studies across illnesses children seemed to place a very high priority on maintaining their normality, and minimising difference, in relation to peers, or to their pre-illness lives (Sutcliffe et al. 2004; Pradel et al. 2001; Miller 1999; Zahorik 1990); Walsh 1983; (my fieldwork study). Children with diabetes were reported as feeling an acceptable 'everyday' degree of normality to be achievable:

> In time it is possible to adjust to the diabetic lifestyle, accept its demands and fit in as part of everyday life. (Miller 1999)

I described here a range of reported attitudes and behaviours that might be understood to relate to a desire on children's part of maintain a sense of normality:

- wanting to hide the illness from others (Sutcliffe et al. 2004; Zahorik 1990):

> Another child stated that her physical attributes gave her away. She said, "Yes, people can tell [that I have this condition]. I'm the only one in the class that's skinny. I feel sad that they know. I don't want them to. One time a friend shouted it out and everyone heard and the friend laughed. It hurt my feelings. It happened in nursery school. I didn't tell anyone then because I was too scared." (Zahorik 1990)

- playing down the severity of the illness, or any concerns or worries (Sutcliffe et al. 2004); (Pradel et al. 2001; Ireland 1997; Walsh 1983) (my fieldwork) - this may also be linked to an expectation from adults that children bear their illness and regimen uncomplainingly and with minimum fuss (my fieldwork) or desire not to worry adults (Dell Clark 2003):

> George: Well it's not a big deal really [having to start insulin injections].
> Mother: He gets a bit nervous… he gets a bit panicked about it.
> (Sutcliffe et al. 2004)

- playing down expertise about the illness (Sutcliffe et al. 2004) (my fieldwork):

> Just how keen the children are to [be 'normal'] is demonstrated by John's comments, when he was asked what advice he would give to a newly diagnosed boy similar to his age.
> John: I'd say, 'Ask someone who's really got diabetes.' I don't think I act like a, I don't think I'm a good person to ask about diabetes, because I'm more of an novice at diabetes. I just know the basics, I know what to do at what times, I know it works out OK.
> Interviewer: From your experience though?
> John: I don't know, I'd say, 'Go and ask someone else.' Because also I, it's too serious and deep for me and I'm just having fun, not like saying 'Oh diabetes...' (Sutcliffe et al. 2004)

- stressing sameness to peers/ siblings and the pre-illness self, sometimes with a degree of bravado or defiance (Miller 1999; Rudestam et al. 2005; Sutcliffe et al. 2004; Walsh 1983; Zahorik 1990)(my fieldwork):

> "I get to do the same things other people do." (Zahorik 1990)
>
> By his picture David wrote: "DON'T LET AN INSULIN PEN PLUS NEEDLE CHANGE YOUR LIFE. YOU'RE JUST THE SAME AS YOU WERE BEFORE." (Sutcliffe et al. 2004)
>
> "I'm not going to let asthma ruin my life!" (Walsh 1983)

In my fieldwork report I suggested that some children with diabetes adopt approaches that allow them to retain their self-worth in terms of being 'normal' while still adhering to the imperatives of the regimen. These are: internalising some of the imperatives of the regimen, for example, disliking, or pretending to dislike, restricted foods (Sutcliffe et al. 2004)(my fieldwork); or seeing having diabetes as an opportunity to live and eat healthily, or to adopt another identity, for example, being very sporty, where those priorities are also foremost (Miller 1999; Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork):

> Confident children tended to cover over differences and the questions of 'being normal':
> Katherine: If you go to football, or you're going round to your friend's house and they have food... do you ever feel different from [your friends] in any way, around that kind of thing?
> George: Not really.
> Mother: He doesn't really like to say
> George: I don't really eat a lot of food. I'm not a big eater.
> (Sutcliffe et al. 2004)

> Diabetes provides an opportunity to learn new things and look after yourself better. (Miller 1999)

In several studies across illnesses children were also sometimes described as choosing to continue with their day-to-day activities instead of interrupting these to take medicines, otherwise attend to their regimen or carry out preventative measures. So, for example, some children with asthma were reported to ignore the onset of warning symptoms (Ireland 1997; Meng & McConnell 2002; Pradel et al. 2001; Walsh 1983), to skip use of preventative medicine (Koinis Mitchell 2003), or not actively avoid triggers (Dell Clark 2003; Meng & McConnell 2002; Pradel et al. 2001); and children with diabetes were described as sometimes 'sneaking' restricted foods (Dell Clark 2003; Zahorik 1990) (my fieldwork), joining in vigorous exercise without first having a snack (my fieldwork), or skipping injections (my fieldwork). As I have already described, several authors proposed the explanation of this to lie in children's lack of understanding of the importance of following the regimen (Meng & McConnell 2002; Pradel et al. 2001). However, in other studies children themselves were reported as explaining that they do this because they do not wish to interrupt their activities (Koinis Mitchell 2003; Walsh 1983) or want to join in with the same things that peers are doing (my fieldwork):

> Many children also mentioned that they "forget" to take their medicines as prescribed by their doctor and tend to become "preoccupied" with other activities such as socializing with friends and "forgetting the pump because I am not tuned into what I am doing" which was a common response. (Koinis Mitchell 2003)

Dell Clark reports that children with asthma disliked using the peak-flow meter because it was an instrument of assessment rather than support – '…there was a pronounced tendency for the peak-flow meter to be regarded by children as a challenge to do well, implying that a child should "feel bad" when not achieving maximum levels."

These findings chime with suggestions from several authors that sometimes following the regimen, or practitioner recommendations, is simply not an attractive option for children (Koinis Mitchell 2003; Meng & McConnell 2002; Walsh 1983).

An alternative approach to understanding the importance of being 'normal' is offered by Ireland in her study of children with asthma (Ireland 1997). She suggests that with the onset of their illness children structure their personal experiences of the illness into a new understanding of what is 'normal for me' which changes over time in line with children' changing experiences of their asthma. This then sets new 'baselines' against which children monitor and appraise their experiences. Further, Ireland suggests, in relation to children's decision-making to sometimes depart from the regimen, children decide to do this in circumstances where they do not have confidence in their ability to control their illness, perhaps because of disbelief in the effectiveness of medicines – an issue raised by other children with asthma (Boyle et al. 2004; Pradel et al. 2001)- or because of external barriers, such as lack of access to medicines in schools (Ireland 1997).

Finally, children across illnesses were described as enjoying the 'normalising' experience of meeting others with their illness (Miller 1999), particularly at asthma camp (Dell Clark 2003; Walsh 1983) or diabetes camp (Dell Clark 2003; Zahorik 1990):

> "I haven't seen so many people with asthma. I fit right in."
> (Walsh 1983)

The importance of sharing care with parents: Children across illnesses were reported as implementing some parts of their regimen independently. For example, children with asthma were described as using relaxation and breathing exercises and rest breaks autonomously (Koinis Mitchell 2003; Walsh 1983); while some children with diabetes were described as doing blood tests, or responding to high blood glucose (by drinking water) independently of adults (Spezia 1991; Sutcliffe et al. 2004; Zahorik 1990) (my fieldwork). However, across illnesses and ages children were described as reporting parents as playing a central role in their care, for example, reminding them to take medicines and giving advice about management (Koinis Mitchell 2003; Walsh 1983) (my fieldwork):

> "My mom has a schedule [for taking medicines] that I should follow, she reminds me." (Koinis Mitchell 2003)

- or, specifically in the case of children with diabetes, taking charge of meal preparation and planning, doing some injections and blood tests, and overseeing and monitoring children's general physical condition (Dell Clark 2003; Miller 1999; Spezia 1991; Zahorik 1990),:

> Dietary maintenance was primarily the responsibility of mothers in the study. They did the meal planning and preparation of school lunches and snacks. (Spezia 1991)

> Over time, I came to realize that each mother (and now and then, a father) served as a kind of "remote-control pancreas" - a label that parents acknowledged as fitting. The parent caretaker monitored and took into account everything the child did and then dispensed food or insulin accordingly. It was common for the vigilant parent to notice when a child seemed "low," and to intervene to stave off a crisis. (Dell Clark 2003)

In my fieldwork study, children either rated their parents as 'joint' carers alongside themselves, or as taking an even more important role in care than they do themselves.

For children with diabetes it seemed that parental involvement in the regimen could be time-saving, for example, eliminating the need for children to wait for the test result to appear on the blood glucose meter – "it's boring sitting there waiting for 2 minutes" (Zahorik 1990) – and thus reducing the extent to which doing tests interrupts other activities:

> "I just check my blood and that takes a minute, which my mom just pricks my finger and I wipe off my finger from blood. I just go ahead and play and she is already doing it for me. So, I can do my own stuff that I have to get done..." (Spezia 1991)

In her study of children with asthma, Pradel found 7 year-olds not to use medicine unless supervised (Pradel et al. 2001). She and Boyle found greater number of older children (approximately 10-12 years) to take medicines independent of adult supervision than their young peers (approximately 6-8 years) (Boyle et al. 2004; Pradel et al. 2001). Younger children (approximately 6-8 years) in Nabors' study of the experiences of children with diabetes at school with diabetes were reported as saying that their parents supported them during participation in sports, whereas children in their early teens requested their sports coach have more knowledge of diabetes, implying that they are relying less on parental support during sports participation by this age (Nabors et al. 2003).

Parents were also described as a significant source of information for children about the illness and regimen (Spezia 1991; Zahorik 1990) (my fieldwork), and, in my fieldwork, I found children learned from them simply by watching their completion of routine tasks such as blood tests or injections.

Carers - and teachers - are also described as taking steps to try to ensure the psychosocial well-being of children with diabetes – for example, giving alternative treats to food for children at times of celebration (Dell Clark 2003; Zahorik 1990), although Dell Clark suggests that they do not always realise that children felt these did not compensate for missing out on food available to other children (Dell Clark 2003):

> Children grumbled in interviews about being diabetic at Halloween, despite receiving money from parents in trade for their trick-or-treat candy. Parents, feeling that money was an adequate substitute for treats, were typically shielded from (and unaware of) the extent of their children's Halloween angst. In private with me, children complained bitterly. (Dell Clark 2003)

Some children across both illnesses were described as reporting friends and family to help them feel less worried about their illness (Koinis Mitchell 2003) and that they felt reassured by parental support of their care (Dell Clark 2003; Koinis Mitchell 2003; Miller 1999):

> When asked where they think they have an easier time taking care of their asthma, 63% of children responded that that they have an easier time managing their asthma at home, "that is where I feel more confident and comfortable". This comfort was relational in nature and they associated the confidence of controlling their asthma at home with the support from their parents and loved ones.
> (Koinis Mitchell 2003)

Two authors of studies of children with diabetes described how a special bond can emerge between diabetic children and their parents, because of the high degree of parental involvement in care (Dell Clark 2003; Miller 1999). One child described this as something that reframes the discomfort of the regimen into a 'kind of loving' (Dell Clark 2003). Rudestam found that children with asthma prefer environments where family members are present – compared with children without asthma who state a preference for environments with peers (Rudestam et al. 2005), and some children across illnesses described disliking being alone in case they became ill (Rudestam et al. 2005; Dell Clark 2003; Spezia 1991).

Children across illnesses were described as appreciating support from adults other than their parents (Miller 1999): many children with asthma were described as always telling someone whenever they experience breathing difficulties (Koinis Mitchell 2003; Pradel et al. 2001) and children with diabetes demonstrated knowledge of the importance of telling adults in charge about their illness in settings away from home (Spezia 1991):

> Every child displayed a sense of responsibility and decision-making ability after hearing the short story about the scout who was planning an overnight camping trip. Bringing insulin supplies and informing the scout leaders about their diabetes were unanimously included. (Spezia 1991)

Some children with diabetes reported transferring the sense of security derived from wearing medical tags - which would identify them to others as diabetic in times of emergency - into the jewellery itself:

> The security symbolized by ID jewellery was evident in the feelings of safety children professed about it. "You never have to take it off, so you feel better," was how one boy expressed it. (Dell Clark 2003)

Finally, Dell Clark expressed the view that carers make less effort to adapt their lives to the needs of children with asthma than children with diabetes, and that this might be linked to asthma being seen as a less serious illness than diabetes:

> In short, a kind of passivity or perhaps learned helplessness typified many families' experience of asthma. To be sure, this may reflect the difficulty of implementing asthma prevention, or it may reflect how families are educated or treated in the medical system. But to a striking degree, passivity was not nearly as characteristic among families of diabetic youth. Why such a contrast? Could the unequal level of initiative and action derive from the cultural interpretation of the two illnesses, that is, that diabetes is more dire. (Dell Clark 2003)

The importance of play: In her study of both children with asthma and children with diabetes, Dell Clark focused on how children used humour, story, ritual, play and prayer to cope with their illness (Dell Clark 2003). She described how children with asthma drew on stories about the powers of superheroes, for example, having Ninja Turtle sheets in hospital, or wearing Ninja Turtle clothes to have allergy injections; and also found much comfort from favourite toys – and even pets despite the fact that they triggered their illness:

> Peter's imagined relationship with the Turtles was one he counted on when he felt sick or anxious. "I think about, like, they'd be real. And they, like, help me try to get rid of. . . stop being sick and everything. They come up and help me." (Dell Clark 2003)

> Even without a formal program of pet therapy, children viewed their pets as sources of comfort, to hug and cuddle closely when sick. A pet could be an imagined protector or "guard dog," carrying a sense of security. A cooperative gerbil, rabbit, dog, or cat might be an ever-available play companion with whom to act out issues of illness. This was high irony if an allergy to the pet was at issue. (Dell Clark 2003)

She also described how children with diabetes drew on stories about the powers of superheroes to help them cope with their illness and treatment, for example, giving an imaginary Pink Panther character insulin injections or taking a Power Ranger toy along to the clinic:

> A diabetic boy, Carl, took a toy version of the Power Rangers TV character White Ranger to the doctor's office for his checkup and lab test, privately imagining that the White Ranger also had diabetes. The toy was a form of moral support as a character known to be powerful; in Carl's words, "You can count on him." (Dell Clark 2003)

Children with diabetes also showed play to be an important coping mechanism, for example, enjoying a fantasy board game about eating sweets, having a teddy bear that had his own diabetes treatment supplies, and taking pleasure in role reversal play such as pretending to be the doctor doing injections with a toy syringe:

> Diabetic children in this study zealously took on the pretend role of doctor, parent, or veterinarian, dispensing shots through a toy syringe. The recipient might be a human playmate, a sibling, myself (as interviewer-playmate), or very often a toy animal or doll.
> (Dell Clark 2003)

Dell Clark reported that children developed rituals to help them cope with treatment, such as hitting the parent after the injection, singing, being hugged, holding their breath or breathing slowly and evenly during the injection. She described how some children made up for the intrusion of injections on their physical person by resisting the rotation of injection sites, or taking some control over this – 'I like to do my stomach in the morning and my hip at night'.

Dell Clark found experiences of diabetes or asthma camps were important to children in terms of normalising their experience of their illness and regimen and providing opportunities for subverting this via humorous and playful games and songs:

> At diabetes camp, a favorite and happily remembered activity was creating visual art using syringes and paint, an activity that placed the medicinal syringe in the role of a fun, expressive medium. At asthma camp, an involving hands-on activity was using nebulizer machines to inflate balloons, thus reframing a medical device into light-hearted entertainment. Among asthmatic peers, playful use of spacer devices (usually used with inhalers, with a sound signal to indicate improper use) spread widely; spacers took on shared uses as intentional noisemakers or quasi-musical instruments. (Dell Clark 2003)

In this section I have described how important sharing care with parents and maintaining 'normality' were found to be for children in managing their illness – and how Dell Clark (Dell Clark 2003) highlighted the role of play and the imagination in helping children cope with their illness and care. In the next section I set out what studies reported children to find unhelpful in managing their illness and care.

13.7 Unhelpful structures

As well as identifying factors that helped children manage their illness and care, studies also reported children to find unhelpful some structures in schools and the wider environment.

Managing at school: Koinis Mitchell found children to report feeling confident about managing their asthma at school when they knew they could ask a teacher or the nurse for help (Koinis Mitchell 2003):

> [Children's confidence] was associated with the feeling that they could ask their teacher/nurse for help if needed...
> (Koinis Mitchell 2003)

However, Walsh found children to describe teachers as over-cautious and restrictive in relation to their illness (Walsh 1983):

> Many complained that the "teachers are so cautious", explaining that their full participation in activities, especially those of a physical nature, was discouraged. (Walsh 1983)

Children were reported to be concerned about lack of access to medical supplies in schools (Ireland 1997) (my fieldwork) and, as already described, Ireland believed this to influence their decision-making about management (Ireland 1997):

> Finally, the child's own decisions to pay attention or to leave asthma behind appeared to be influenced by empowerment issues. These related directly to the degree of responsibility they were permitted with regard to inhaler use while at school and to their awareness of the support available. For example, one child was not sure whether she had to wait to ask for her inhaler until the end of her lesson despite the onset of symptoms. (Ireland 1997)

Several studies of children with diabetes found systems around children's maintenance of their regimen in schools sometimes magnified children's sense of difference from their peers (Sutcliffe et al. 2004; Miller 1999;):

> Uncoordinated care could disrupt children's lives. A boy who had to have an injection and snack at school found that the school staff interpreted the doctor's prescribed routines in ways that stopped him from enjoying playtime with his friends when he had to go over to a remote part of the school for his care. (Sutcliffe et al. 2004)

> The differences between you and your friends appear greater when there are variations in the school timetable. (Miller 1999)

Nabors' study with children with diabetes focused particularly on children's experiences of managing their care at school. Chiming with Sutcliffe's finding about the lack of knowledge of some schools staff about diabetes, and Koinis Mitchell's findings that some children with asthma were concerned about their teacher not knowing what to do if they got ill (Koinis Mitchell 2003), Nabors reported children calling for teachers (especially sports coaches) and nurses to receive more education about their illness:

> Children of all ages at both camps reported that teachers, nurses, and friends needed to improve their knowledge about diabetes.
> (Nabors et al. 2003)

Children were described as reporting that it would be helpful if teachers were flexible about letting them do blood tests or resting, even when this clashes with the school timetable – and without calling to much attention to them:

> Children also talked about teachers needing to be flexible. Children reported that teachers should let them test their blood sugar again if their results were low. Also, children said or wrote that they needed to take breaks when feeling low, even if the teacher was in the middle of a lecture or if they were taking a test. They wanted their teachers to understand and not call too much attention to them when this need occurred. (Nabors et al. 2003)

Children were described as wanting to be able to access diabetes supplies at school at all times and that several had concerns about the school nurse not being available every day to help them if they suffered hypoglycaemia:

> Both older and younger children also reported that having their test kits and snacks available whenever they needed them was important. Several children reported that nurses did not come to their school every day, and they worried about what might happen if they "got very low" and no one was there to help them. (Nabors et al. 2003)

The author suggests that schools need to ensure medical care is available even on days when the nurse is not on site in order to relieve children's anxiety about lack of medical support. She also reports that children felt it would be helpful if staff could tell when they are 'very low' as opposed to 'a little low', and if friends helped them by alerting others and getting them to the nurse's office when this happened. Children were described as saying that they would like reminders about snacks and tests, though there was a "fine line" between the right amount and too many reminders, and - like some children with asthma in Walsh's study - some did not want to discuss their illness or care with peers (Nabors et al. 2003; Walsh 1983). Children were described as finding participation in after-school activities difficult because of lack of access to supplies:

> Children mentioned that participating in after-school activities was difficult. Nurses were not always on site, and their supplies were often locked in the nurse's office. (Nabors et al. 2003)

On the basis of this, Nabors concludes that children should be involved in developing school action plans around diabetes so that their individual preferences around care can be incorporated (Nabors et al. 2003). Sutcliffe suggests that the wider political environment reduces school staff ability to meet the needs of children with chronic illness with flexibility and resourcefulness:

> [Diabetes nurses] work against a culture of discrimination against disability in some schools, reinforced by league tables and schools competing against one another, so that students who take up more staff time (cost more) and who may fail are unwelcome in competitive and under-resourced schools. (Sutcliffe et al. 2004)

Impact of socio-economic factors: Authors of several studies also highlighted how the wider socio-economic environment directly impacts on children's and families' ability to cope with illness and care. In line with findings from quantitative research that adjustment to chronic illness may be especially hard for those living in very stressful circumstances (Amer 1999; Bradley & Gamsu 1995), I suggested, in my fieldwork study, that it seemed that for some families in the sample the accumulated stresses of poor housing and low social support left relatively few psychosocial resources for grappling with the disruption of living with diabetes and its regimen. While I found that good provision of interpreting services and awareness of the impact of the regimen on activities associated with maintaining ethnic identity were important, I concluded that it is the interaction of cultural or linguistic difference with the poverty and social exclusion associated with minority ethnic status (Karlsen & Nazroo 2002; Spencer 1996) - rather than cultural difference per se - that seemed to impact most significantly minority ethnic children's experiences of their illness and care. I also observed that cultural stereotypes, for example, about the support of large or extended families within Black or Asian culture, can be inaccurate and potentially damaging.

Two of the other authors who raised the issue of socio-economic disadvantage, suggested this as part of an explanation for children's 'failure' to follow their care regimen – that it either compromised parental support or children's ability to attain certain levels of knowledge:

> There may be many reasons for failure to make treatment decisions. Issues such as single parenting, low income, and job demands limit parental availability for some children. (Meng & McConnell 2002)
>
> Often, it is the correlates of neighborhood disadvantage (poverty, cultural dislocation, lack of access to optimal health care, violence, etc.) that may act as impediments to attaining optimal knowledge levels. (Koinis Mitchell 2003)

Sutcliffe suggested that alongside awareness of the impact of the wider socio-economic environment on children and families' ability to cope, the social quality of life for individual children may also be important (Sutcliffe et al. 2004). This chimes with findings from my own research study that two children in particularly difficult life circumstances seemed to be findings adjustment to life with diabetes especially challenging.

Finally, in relation to the wider physical environment, Rudestam pointed out how developing cleaner, less polluted inner-city environments would benefit not only children with asthma (Rudestam et al. 2005):

> Focusing on the larger issues of place and outdoor pollution is important in curtailing the rate of asthma, encouraging political participation and community involvement, and transforming outside environments into places that are not regarded as dirty and threatening. As lay involvement in asthma increases, disease discovery, treatment and prevention can be regarded more holistically, not just as a function of a 'trigger-free' environment, but of better living conditions and broad social change.
>
> (Rudestam et al. 2005)

In this section I have summarised how structures at different levels – in the micro-environment of the school and in the wider social-economic environment – can hinder children and families' ability to manage their illness and care. In the next section I describe what children in the studies reported about their experiences of clinical care.

13.8 Experiences of clinical care

Children with diabetes were reported to say that they appreciated positive feedback from clinicians and that they felt valued for their contribution to care (Miller 1999). Children across several studies were described as being familiar with the workings of their diabetes clinic (Zahorik 1990) (my fieldwork), although many – though not all – reported that they wanted parents or carers to do much of the talking in clinic (Sutcliffe et al. 2004) (my fieldwork).

> It is important to receive positive feedback from doctors and nurses. (Miller 1999)
>
> The children knew the clinic routine well and would, for example, inform their parents that they still had not been weighed by the nurse, or were waiting for a blood check. (Zahorik 1990)
>
> Whereas some children are keen to take a leading part in discussions, others prefer to use their parents as mediators, interpreters, negotiators or defenders. (Sutcliffe et al.2004)

In my fieldwork – and in line with previous work in the same area - I found school-age children are not routinely included in discussions of their illness and care. I raised concerns that children's active involvement in their care in home settings contrasted strongly with their passive role in clinic interactions and that, further, this meant that when children were praised for their personal contributions to care or exhorted by staff to a more active involvement in care at home, clinicians' words were undermined by the model of child as passive conveyed by the rest of their actions and words. On the other hand, Sutcliffe points out that 'children vary and change, and genuine ways to involve them start from the child's own terms, rather than enforcing a standard method', such as requiring that they communicate directly with clinicians. She suggests that:

> Sometimes, when parents speak for the child this can help to equalise the power sharing between the child and adults, such as by protecting the child from direct attention, possible criticism or blame about, say, high blood sugar levels. Parents can field awkward questions, proffer excuses, sort out misunderstandings, and generally relieve pressures on the child. (Sutcliffe et al. 2004)

Sometimes children were reported to find information from clinicians unclear – particularly immediately after diagnosis - because of their use of professional terminology (Zahorik 1990) (my fieldwork):

> The children's responses of explanations gained after diagnosis reflected varying experiences with health professionals, such as confusion with professional terminology' "I don't really remember. There were a lot of technical words and stuff, but I don't really remember them." (Zahorik 1990)

However children were described as valuing the expertise and understanding of specialist clinical staff, in particular the DSN (Sutcliffe et al. 2004) (my fieldwork).

> The specialist diabetes staff that children and parents came into contact with received the highest praise. The knowledge and experience of these staff was well respected by children and parents alike… Parents and children also appreciated the kind manner and respect they received from the specialist staff at the clinic.
> (Sutcliffe et al. 2004)

Children with diabetes, and their families were described in one study as expressing concern about the lack of expertise and sympathy from non-specialist staff (Sutcliffe et al. 2004):

> Although only 24 families were interviewed, most of the parents' and some of the children's accounts of support and care included at least one incident about generalist staff - GPs, nurses, A&E (accident and emergency) and general paediatric ward staff, and other adults such as school staff -lack knowledge and insight. The accounts often describe seriously inept care of these children by nonspecialists.
>
> (Sutcliffe et al. 2004)

Sutcliffe reports these problems to include GP failure to recognise paediatric diabetes, and lack of knowledge about diabetes and understanding of the emotional needs it engenders on the part of ward and A&E staff (Sutcliffe et al. 2004).

Appendix 14: Tabulation of study themes for narrative synthesis

Diabetes studies

	What seems to improve children's day-to-day experiences of their illness/care	**What seems to worsen children's day-to-day experiences of their illness/care**
Spezia (nursing)	**Children's competencies/beliefs** Active use of interventions Feeling normal Knowledge of timetable Knowledge of interventions Recognition of symptoms **Regimen** Choice over injection sites **Wider environment** Accessible info from clinicians Camps Medi-care tag Parental support Peer support Relatives with diabetes Teacher support	**Children's competencies/beliefs** Difficulty recognising hyperglycaemia **Regimen** Regimen undermines being same as others **Wider environment** Peer fear of contagion
Zahorik 1991 (n/k)	**Children's competencies/beliefs** Active use of interventions Empirical understanding Feeling normal Knowledge of clinic / routine Knowledge of interventions Knowledge of regimen Knowledge of timetable Recognition of symptoms Some bio-med understanding Vigilance for symptoms Chances to have treats Regimen as opportunity to be healthy Sense of control (day-to-day and re future mortality/morbidity) **Regimen** Effectiveness of regimen **Wider environment** Accessible information Additional parental attention Camps Peers treat them 'normally' Siblings treat them 'normally'/support	**Children's competencies/beliefs** Decision-making: cheating on diet Misunderstandings of management tasks **Illness** Tiredness and interruption with school work **Regimen** Injections; restricted diet; finger prick; regular injections/tests; no sleepovers; regular meals; **Wider environment** No/unclear explanations from clinicians or parents Sibling/peer teasing Teacher inflexibility Visibility of regimen (dislike eating snacks in school)
Miller (nursing)	**Regimen/ wider environment** Accessible information Additional parental attention Chances to have treats Feeling normal Meeting others with illness Over time management becomes 'normal' Parental support Peer support Positive clinical feedback	**Illness** Worries re long-term health Grief and relief at diagnosis **Regimen** Physical: restricted diet; finger pricks Social: restricted diet; regular injections/tests/meals **Wider environment** School structures Teasing

	Regimen as opportunity to be healthy Teacher/nurse support	
Nabors 2003 (clinical)	**Wider environment** Access to supplies Improved nurse/teacher knowledge Peer support Teacher flexibility	**Wider environment** Access to supplies / medical expertise
Sutcliffe 2003 **(social science)**	**Children's competencies/beliefs** Active use of interventions Cyclical learning over time Empirical understanding Feeling normal Flexible provision of information over time Knowledge of timetable Knowledge of interventions Sense of control **Environment** Peer support Specialist staff Teacher/nurse support	**Children's competencies/beliefs** Sense of lack of control **Environment** Emergency treatment Lack of information sharing across families Non-specialist staff School structures
Dell Clark 2004 (diabetes data) **(social science)**	**Children's competencies** Empirical understanding Knowledge of interventions Knowledge of timetable Some bio-med understanding **Wider environment** Camps Control over sites Medi-care tag Parental support Play, religion, ritual, stories, humour	**Illness** Night-time hypoglycaemia **Regimen** Emotional disruption: diet; injections; Physical disruption: tests; injections (worse than parents believe); diet (worse than parents believe) Social disruption: tests, injections; diet;
My fieldwork 2006 (social science)	**Children's competencies/beliefs** Active use of interventions Competence alongside carers Cyclical learning over time Empirical understanding Feeling normal Internalising regimen Knowledge of clinic / routine Knowledge of timetable Knowledge/use of interventions Parental support School structures **Regimen** Decision-making: internalise regimen or assume identity with similar regimen	**Children's competencies/beliefs** Decision-making: ignore regimen to reduce interruption Decision-making: re-interpret regimen to maximise 'treats' **Illness** Sickness from glucose imbalance; fear re long-term complications **Regimen** Physical: Relentlessness of injections/tests; pain of injections; diet Emotional: blood glucose imbalances, diet, relentlessness of injections/tests; adult enforcement Social: relentlessness and interruption of injections/tests; impact on activities important to maintaining ethnic identity **Environment** Active participation at home v lack of participation at clinic Technology Socio-economic stresses Inflexible interpreting services

Asthma studies

	What seems to improve children's day-to-day experiences of their illness/care	What seems to worsen children's day-to-day experiences of their illness/care
Walsh 1983 (nursing)	**Children's competencies/beliefs** Active use of interventions Convenience of autonomous interventions Effectiveness: regimen Empirical knowledge Hope: that they would outgrow their asthma Illness as adjunct to self not integral part of self (asthma treated as an acute illness) Knowledge of regimen Knowledge of triggers Knowledge interventions inc stepwise approach **Regimen** Effectiveness of inhaler Looking after illness becomes 'normal': physical disruption eases **Wider environment** Camps	**Children's competencies/beliefs** [implied by author as barrier] children's poor bio-medical knowledge Decision-making: ignoring early warning symptoms because of lack of knowledge: asthma as not being able to breathe instead of difficulty breathing Decision-making: ignoring early warning symptoms in order to be normal (asthma treated as an acute illness) Decision-making: ignoring regimen in order to be normal (asthma treated as an acute illness) **Illness** Breathing difficulty and other symptoms Fear **Regimen** Financial burden of interventions Physical: injections Social: degree of medical intervention makes you feel different Peer teasing Teachers' over-caution
Ireland 1997 (nursing)	**Children's competencies/beliefs** Active use of interventions Decision-making affected by belief in ability to control and feeling 'normal' Knowledge of interventions Planning ahead to minimise disruption Vigilance for symptoms **Regimen** Effective regimen endorses normality	**Children's competencies/beliefs** Lack of belief in ability to control **Illness** Fear Feeling different from others **Regimen** Access to supplies Regimen undermines normality

	What seems to improve children's day-to-day experiences of their illness/care	What seems to worsen children's day-to-day experiences of their illness/care
Pradel 2001 (other clinical)	**Children's competencies/beliefs** Active use of interventions: 12 yr olds more autonomously and using more comprehensive range of interventions than 7 yr olds Knowledge of environmental triggers (12 yr olds) Knowledge of interventions Knowledge of symptoms inc 'wheezing' **Wider environment** Re-education of children at each new 'stage of cognitive development' Standardisation of medicine packaging (younger children recog medicines by their physical characteristics eg colour) **Regimen** Effectiveness: medicines	**Children's competencies/beliefs** Decision-making: 'Step-wise' approach to managing attack not understood Decision-making: ignoring early warning symptoms because of lack of knowledge (asthma as not being able to breathe instead of difficulty breathing) Decision-making: not avoiding triggers despite 12 yr olds having good knowledge of these Decision-making: not using peak flow meter Decision-making: lack of understanding about the role of preventive medicine **Illness** Fear **Regimen** Ineffective interventions Medicines make you feel sick Nasty taste of medicines Social disruption: having to stop to take medicines – younger only (convenience of autonomous interventions)
Meng 2002 (nursing)	**Children's competencies** Knowledge of early warning symptoms Some trigger avoidance Some use of peak flow meter **Wider environment** Parental support	**Children's competencies/beliefs** Decision-making: Ignoring early warning symptoms because incapable of understanding that this will lead to a worsening of symptoms Decision-making: Ignoring early warning symptoms because of wanting to be 'normal' Decision-making: Not avoiding triggers (asthma treated as an acute illness) **Illness** Worries about shortness of breath, seasonal symptoms, going to hospital, running out of medicines, missing school Sadness at having asthma **Wider environment** Inaccessible supplies esp in PE Not having control over slow warm ups in PE Socio-economic stressors

	What seems to improve children's day-to-day experiences of their illness/care	**What seems to worsen children's day-to-day experiences of their illness/care**
Koinis Mitchell 2003 (other clinical)	**Children's competencies/beliefs** Active use of interventions Fear: feeling bad makes me be more careful Hope: of growing out of asthma and growing abilities to manage asthma Improved management skills/confidence over time Knowledge of interventions inc step-wise management Knowledge of timetable Sense of achievement gained from autonomous and/or problem solving management of illness Technical: setting watch to times when need to take medicine **Wider environment** Parental support vital – home a 'safe place' Teacher/nurse's support vital	**Children's competencies/beliefs** Decision-making: ignore medicines when with friends **Illness** Fear: I forget more when I feel bad about it **Regimen** Dislike of medicines Dislike of avoiding triggers Social disruption: taking inhaler **Wider environment** Socio-economic stressors
Boyle 2004 (nursing)	**Children's competencies/beliefs** Knowledge of how to take inhaler (only younger need supervision) Recog medicines by their physical characteristics eg colour) **Regimen** Effectiveness of inhaler **Wider environment** Mothers taught older children to take inhaler by themselves	**Children's competencies/beliefs** **Illness** Fear Symptoms – worse in winter **Regimen** Nasty-tasting medicines Not being able to have pets Not being able to do sports Ineffective interventions **Wider environment** Clinicians may not be sensitive to African-American use of general or upper airway symptoms descriptors yet white children in other studies used similar descriptors Having to catch up with school work
Dell Clark 2004: asthma data (social science)	**Children's competencies/beliefs** Awareness of triggers Empirical understanding Hope to grow out of asthma Some learning of bio-medical understanding **Regimen** Effectiveness of nebuliser/inhaler Humour at camp **Wider environment** Ritual, play, story, humour, religion,	**Children's competencies/beliefs** Dislike of being alone **Illness** Fear: hidden from adults **Regimen** Nasty tasting medicines Peak flow meter rarely used cos assessment not relief (asthma treated as an acute illness) Social disruption: nebuliser; Spacer noise amusing not disincentive to inhale quickly **Wider environment** Embarrassed re inhaler (peers) Peak flow meter rarely used cos families not been shown it

	What seems to improve children's day-to-day experiences of their illness/care	**What seems to worsen children's day-to-day experiences of their illness/care**
Rudestam 2005 (social science)	**Children's competencies/beliefs** Awareness of importance of assistance from others Awareness of triggers and desire to be away from them Empirical understanding of illness based in own exp Enjoy relating exp of illness Preventive medicine: more readily described reactive treatments Sense of control via achievement of daily management tasks/amelioration of symptoms [author suggests teaching management skills to ameliorate sense of powerlessness] **Wider environment** Recognition of relationship between asthma/poverty and effort to empower and improve inner-city communities	**Children's competencies/beliefs** **Illness** Fear/powerlessness esp in environments with triggers **Regimen** Social disruption of trigger avoidance: wanting to play outside esp in order to be with friends

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Glossary

DSN	Diabetes Specialist Nurse
DKA	Diabetic ketoacidosis
NS	Narrative Synthesis