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The challenges of optimising glycaemic control in children with type 1 diabetes: a qualitative study of parents' experiences and views

Running title: The challenges of optimising glycaemic control in children

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Novelty statement:

- We draw upon ~~First qualitative study drawing on~~ parents' perspectives to understand ~~and explore~~ why children with type 1 diabetes experience sub-optimal glycaemic control.
- It is not parents' fear of hypoglycemia in isolation which leads them ~~to decide~~ to elevate their child's blood glucose but, rather, parental fear in conjunction with other factors and considerations.
- Parents operationalize two sets of bloods glucose targets with tighter targets used when the child is under their direct care, and looser targets when in other people's ~~the care of others~~.
- Parents think health professionals have unrealistic expectations of what they can achieve with regards to their child's glycaemic control.

Abstract

Aims: To explore the difficulties parents encounter achieving clinically recommended blood glucose levels and how they could be better supported to optimize their child's glycaemic control.

Methods: In-depth interviews with 54 parents of children with type 1 diabetes (≤ 12 years). Data were analysed thematically.

Results: Parents described being reluctant and finding it difficult to ~~always~~ keep their child's blood glucose levels consistently within clinically-recommended ranges. As well as worrying about their child's ability to detect/report hypoglycaemia, parents highlighted a multitude of factors which impacted on their child's blood glucose levels and over which they could exercise little control. These included: leaving their child with other caregivers who could not be trusted to detect hypoglycaemia; difficulties remotely monitoring and regulating their child's food consumption and activity; and, physical and social changes accompanying childhood development. Most parents used two sets of blood glucose targets, with clinically recommended targets employed when their child was in their immediate care and higher targets when in the care of others. Parents described health professionals as lacking understanding of the difficulties of keeping blood glucose within target ranges and needing more empathetic, tailored and realistic advice.

Conclusion: It is not parents' fear of hypoglycaemia in isolation which leads to decisions to raise their child's blood glucose but, rather, parental fear in conjunction with other factors and considerations. Hence, to improve diabetes management in children these factors may need to be addressed; for instance, by training others in diabetes management and using new technologies. Changes to consultations are also recommended.

Key words: Type 1 diabetes mellitus; fear of hypoglycaemia; blood glucose control; parents; qualitative research

INTRODUCTION

Type 1 diabetes usually develops in childhood or adolescence and its incidence is rising rapidly globally [1]. Good blood glucose control in childhood can significantly reduce [the risk of](#) complications in adulthood. However, many children experience sub-optimal control, with a Scottish study finding only 10% achieve the clinically recommended blood glucose target of <58 mmol/mol (7.5%) [2], and other UK data showing that approximately a quarter of children and young people have an HbA_{1c} of >80mmol/~~mo~~-l (9.5%) [3]. Amongst non-adolescent children, parents assume much responsibility for diabetes management, including: checking blood glucose levels, determining and administering insulin doses, carbohydrate counting, and preventing hypoglycaemia and hyperglycaemia.

While poor glycaemic control amongst children is well recognized, [most researchers have used quantitative methods -to attempt only quantitative research has attempted-](#) to explain this issue. This [quantitative](#) research has tended to focus on the impact of parents' fear of hypoglycaemia on adherence to their child's treatment regimens [e.g. 4–6]. A recent systematic review of this research reported that, while fear of hypoglycaemia is common amongst parents, there is a paucity of evidence that it ~~leads directly~~ [leads](#) to parents allowing their child's blood glucose to run higher than clinically recommended to avoid hypoglycaemia [7]. This review recommended that qualitative research be undertaken with parents to [improve understanding of their](#) ~~better understand their~~ attitudes to hypoglycaemia and identify other issues that might influence how they approach and manage their child's blood glucose control.

To address the review's recommendation and broader concerns about suboptimal glycaemic control in children with type 1 diabetes, we undertook a qualitative study with parents of children ≤12 years. Our aim was to understand and explore the difficulties parents encounter achieving clinically recommended blood glucose levels. A key objective was to identify how parents might be better supported to improve their child's glycaemic control.

METHODS

In-depth interviews were undertaken with parents as these afforded the flexibility needed for them to discuss issues they perceived as salient, including those unforeseen at the study's outset [8,9]. The study took general theoretical and procedural direction from Grounded Theory research [10]. This entailed simultaneous data collection and analysis, with findings from early interviews being used to **iteratively** inform areas explored in later ones.

Recruitment and interviewing continued until data saturation occurred.

Recruitment and sample

Parents were recruited by health professionals from four Scottish paediatric departments using an opt-in procedure and purposively sampled so that there was diversity in terms of their child's: age, sex, diabetes duration (at least six months), regimen (multiple daily injections and continuous subcutaneous insulin infusion – CSII) and glycaemic control (HbA_{1c}) and parents': education, occupation, employment status (full-time, part-time) and marital status. The final sample comprised 38 mothers and 16 fathers of 41 children (see table 1), with 14 mother-father dyads choosing joint interviews.

Data collection and analysis

Interviews were conducted by DR, an experienced qualitative researcher, in parents' own homes between November 2012 and June 2013, using a topic guide (see table 2). DR reassured parents he was not a health professional and that the purpose of the interviews was to understand their experiences and not to judge them. Interviews averaged two hours, were digitally recorded (with consent) and transcribed in full.

Interviews were read through repeatedly before being cross compared to identify issues and themes which cut across parents' accounts [11]. JL and DR reviewed all data independently before meeting to compare interpretations, reach agreement on recurrent themes and

findings and develop a coding framework capturing original research questions and emerging findings. Data were coded and retrieved using NVivo, a qualitative software package (QSR International, Doncaster, Australia) and coded datasets were subjected to further analyses.

Ethical approval was provided by the South East Scotland Research Ethics Committee 01, NHS Lothian (12/SS/0071). Below, data are tagged using unique identifiers, with 'M' or 'F' signifying a child's mother or father respectively.

RESULTS

All parents described receiving comprehensive instruction about diabetes management after their child's diagnosis [12] and subsequently; they also described an awareness of the importance of maintaining blood glucose levels within clinically-recommended target ranges (4-7mmol/mol (pre-meal blood glucose~~BG~~) and, 2 hours after a meal, within +/- 2mmol/mol of the pre-meal blood glucose~~BG~~). Despite this awareness, parents described being reluctant and finding it difficult to always keep their child's blood glucose levels consistently within clinically-recommended ranges. While worries about hypoglycaemia were a major concern for parents, they presented a multitude of interwoven factors and considerations to explain poor blood glucose control and their decisions to allow blood glucose levels to run higher than clinically recommended. Below, we describe these findings, which cut across all interviews, in more detail before considering parents' support needs.

Fear of hypoglycaemia

Alongside worries about long-term complications, parents described an ever present concern about hypoglycaemia wherein, "you have that underlying nervousness all the time that something might happen" (02M). Indeed, all parents shared their fears about finding their child unconscious or dead in bed, "you're scared to go into her room in the morning, every morning" (29M); "I feel physically sick" (34M). In some cases, parents' worries were

precipitated by traumatic events, such as when 27M found her son collapsed on the floor “and he couldn’t use his arm and he couldn’t use his leg and one side of his face had fallen and it literally looked like this four year old child had had a stroke.” In others, parents’ worries had arisen from reading “horror stories” (22M) in magazines; or, in 26F’s case, after learning that a colleague with type 1 diabetes had been found dead in bed the same weekend as his child was diagnosed, “which was really horrific.”

Children: unreliable reporters of hypoglycaemia

Parents’ worries about hypoglycaemia were often also driven or compounded by their child’s difficulties detecting and reporting low blood glucose, this being a particular concern for those with infants and toddlers because, “he doesn’t have a clue because he’s just learning to talk” (22M). However, even as children got older, parents continued to worry about their safety, in some cases because the child had never developed hypoglycaemia awareness, in others because children could become so engrossed in activities that they did not notice their blood glucose levels dropping. This included 06M’s “very active” six year old son who, “when he’s on his bike, he’s not really aware of anything apart from the crazy jump he’s built in the garden and he can’t think about being hypo and then, all of a sudden, he’ll get off his bike and realise ‘oh my god.’” Children were also described as being unreliable reporters of hypoglycaemia due to their emotional immaturity:

“she won’t tell you when she’s doing something like swimming because she’s enjoying herself and realises that she’s going to have to stop... and I think ‘poor child’, you know, I’m very adult with her about dealing with it, but she’s not going to be sensible at nine is she really?” (26M)

Monitoring and supervision

To address their worries about their child’s safety, parents described making extensive use of blood glucose monitoring as well as looking out for behavioural and bodily changes which could signal the onset of hypoglycaemia: “sometimes he’ll come and ask for something to

eat and that'll kind of alert you (25M); "you can tell by her glazed eyes or her white skin" (24F). However, as parents noted, for these monitoring activities to be successful, their child needed to be under their close supervision. Hence, many (typically mothers) described giving up work or moving to part-time employment, as well as putting other aspects of their life on hold to keep a close eye on their child and accompany them to parties and on school trips: "it keeps you tied 24,7 so she can run back and do a blood check... but I don't let her see that part, she just thinks I don't go out much" (37M). Parents also described how they would often discourage their child from playing outside their own home or attending sleepovers, "because what if she goes hypo, will the other parent know what to do ... it terrifies me that she's ten and I still won't let her go" (21M).

School/nursery and other settings outside the home

Remote management

Given parents' concerns about their child's safety, sending them to school or nursery could cause considerable anxiety: "I sit here and panic" (01M). To address their anxieties, parents described going to considerable lengths to ~~remote~~-manage and monitor their child remotely. This included 34M who would go into school every morning and ask staff "what's happening today, anything different?" so she could adjust the basal rate on her child's pump accordingly. Parents also described requesting menus so they could work out the carbohydrate contents of their child's lunch and how both they and school staff made extensive use of phone or text communication to establish what children's blood glucose levels were, so that they could advise on the quantity of insulin needed to cover meals/snacks.

Unpredictable situations

Despite their efforts to ~~remote~~-manage their child remotely, parents highlighted many situations which they could not anticipate or control and which could result in their child coming out of school/nursery "down at 2.9 [mmol/L] and she's white as a ghost" (21M) or

with blood glucose levels “sky high” (24F). Parents, for instance, described the difficulties of planning for physical activity because, “a lot of it depends, like if it’s raining they don’t run about as much, whereas if it’s a nice day they’ll run about more” and how this could have “a huge bearing on what their blood sugar is before they leave” (38M). Ensuring their child was given the correct insulin dosage at lunchtime could also present challenges because food in the canteen could run out or change. Parents also suggested that their child could not always be trusted to consume the packed lunch which they had meticulously carb counted for them and described how, “staff don’t have the time to sit and make sure that he’s eating all his lunch.” (15M)

Other people; other contexts

Parents also described encountering similar problems outside the school/nursery setting with many highlighting how, within their social networks, “the ignorance is phenomenal” (02M) and how this resulted in them constantly having to constantly fire-fight and educate others: “The mums and dads in our street are giving her sweets and I’m saying, you can’t do that, she’s diabetic, bringing her home, she’s away up at the twenties.. it’s very frustrating (01M). In some instances, this ignorance was described as extending to grandparents and separated fathers, with the latter often being blamed for high blood glucose levels because, while “he’s done the training as well, because he’s not doing it every day, I don’t think he understands too much.. he tends to give him more treats” (15M). However, it was also noted that moving between parental homes could disrupt routines in ways which could also lead to fluctuations in blood glucose, such as when: “rather than getting his breakfast at quarter to eight, he actually gets his breakfast about nine-ish” (15F).

Cocooning versus accommodating a ‘normal’ childhood

Initial cocooning

All parents suggested that it would be much easier to stabilize their child’s blood glucose if it was possible to keep routines stable and severely restrict activities: “I think 4 to 8 is the ideal

place to be in an ideal world with a child who doesn't do anything" (35M). Indeed, many had attempted to do this in the initial months following diagnosis, including 17M who was: "very regimented when we started... sometimes she'd like to have a long lie in and I'm barking at her cos she's got to get up and she's got to go to sleep at a certain time"; and, 21M who described initially treating her six year old daughter "like a baby, you're having to say to her, 'no you can't have that and you can't do this, can't do that.'"

Relaxing control over time

However, over time, most parents described adopting a more relaxed approach because of the difficulties of getting their child to adhere to strict routines: "an adult can be more disciplined about when they eat and be more regimented in their routine, but a child, they're far more active and if they want to eat something, they want it now (laughs)" (40M). Parents also highlighted the difficulties of regulating their child's eating: "I find the wrappers under the bed" (0028F) and monitoring their physical activity, especially as they got older and acquired greater autonomy.

Accommodating physical and social development

In addition, alongside sudden growth spurts or "hormonal changes and puberty kicking in" (19M) which could cause their child's blood glucose to "suddenly elevate" (34M) or go "completely haywire" (02F), parents described having to accommodate and adapt to social changes accompanying childhood development. Such changes, as parents observed, required frequent recalibration of their child's insulin requirements: "like swimming, she's moved up a level into an older age group and even just the timing of the class changes everything" (17M). Hence, parents described how, in their efforts to try to keep their child's blood glucose within target ranges they continuously had to ~~continuously~~:

"chase a moving target...it changes all the time.. you've got the friendship groups changing, you've got them moving schools, blah, blah, it's just so difficult, it's impossible to stop his blood glucose levels going up and down" (10M).

Constructing and enabling a 'normal childhood'

Parents also shared their worries about the psychological and emotional impact on their child: "it's [diabetes] taking her childhood away from her" (18M); "it's a horrible thing she's got to deal with" (26M). Hence, parents described wanting to protect their child from undue unhappiness and distress; in 21M's case by "carb-ing up" her 10 year old daughter with ice cream and sweets at the weekends to enable her "to have her innocence, to go out and play and feel like a normal child without feeling there is something different with her." Indeed, parents, including 18M, often described witnessing their child's own upset and distress as a tipping point for relaxing food choices and other restrictions:

"her friend's birthday last year, that was the first time she broke down, after having got the diabetes in October, just sorta, first time, really sobbing and just said, 'can I not have diabetes for one night', and that was, you know, the worst... So what we did, I just said to her 'eat what you want' and then I'll correct it later'. And now we do just the same if there's a birthday party" (18M).

'Home' and 'away' targets

To accommodate unpredictability and change, and enable their child to undertake activities without risking severe hypoglycaemia, virtually all parents described using two sets of blood glucose targets. Tighter targets were employed when the child was under direct parental supervision and food consumption and physical activity could be carefully monitored to inform titrated insulin doses: "she's always in single figures when she's with us ... I love it when I've got her home at the weekend, cause I know exactly what's she's eating, what's she's doing, where she's running, where we're taking her" (01M). In contrast, looser targets were often used when parents could not directly monitor their child and predict and plan for their activities, such as when their child attended school and playgroups, or when older children went out to play unsupervised: "when I'm on the case, close by, then we try and keep it low but if he's doing something that I don't know what's going to happen, I'll probably,

well he's usually a little bit higher" (06M). Parents presented their decision to allow high blood glucose levels as "a judgement call" (26F), undertaken primarily as "a safety measure" (34M), their rationale being that it is "better to be a bit too high for a few hours than too low and risk her slipping into a coma" (25M). They also explained that they elevated blood glucose levels because they lacked confidence in others (e.g. teachers), and their own child, to detect hypoglycaemia promptly: "in our care, you see the warning signs coming so we react to it, somebody who doesn't know that won't" (26F).

Minimizing distress

However, some parents also indicated elevating blood glucose levels to avoid risking distressing others, such as the parents of their child's friends, who were "already quite frightened to invite her round to parties in case something happens" (33M). Parents shared their worries that, if such people were to be exposed to hypoglycaemia, future invitations might be rescinded and their child ostracised. In some situations, parents also elevated blood glucose to address their own panic reactions and distress, most typically at night when they described very poor and interrupted sleep because, "psychologically, you're in the room next door thinking what happens if he stutters or something in the night and that's him gone" (23F). Hence, such parents described how "I always make sure she has a really good supper so she doesn't dip in the night" (19M) because, "it gives you peace of mind, you know can get at least some sleep because you know they are safe" (32M).

Experiences of consultations and support needs

Diabetes professionals were widely commended for their clinical knowledge, "he's [consultant] really quick with his facts and figures" (03F). However, many parents described going into consultations feeling "anxious" (016M), because you "think you're going to get told off" (002F) and coming out "demoralized" (14M) and "very upset because you've had 6 months between appointments and, you've tried really really hard, you've bust a gut and you get 'oh their HbA_{1c} is not good enough, you need to do better' and you're thinking, 'what can

I do, I am trying my best” (38F). Indeed, many suggested that consultations were too focused on their child’s HbA_{1c} results, “the Holy Grail of what you’re trying to achieve” (06M), and how they would benefit from more attention being given to their effort: “I’d like them to be more positive about everything you’re doing, you know, a bit more positive reinforcement instead of ‘well other people can do it better’” (38M). Parents also described how clinical decision-making tended to focus on algorithms and growth charts, rather than taking account of their own experiential knowledge of how growth spurts, hormonal changes, physical activity patterns and illness impacted on their particular child’s insulin needs: “they have this book that they follow. I think that frustrates me a little bit, they have these little criteria, but I’ve nursed her through illness before and I know what works and what doesn’t” (03M); “they know certain steps, but they don’t know my child, they just know certain steps of a diabetic, not my child” (01M).

Parents also conveyed their worries that, because, diabetes consultants’ knowledge was “text book” (35M), they had unrealistic expectations of what could be achieved in terms of stabilizing and keeping their child’s blood glucose within target ranges: “they want you to put your child in a box, but unfortunately it doesn’t work that way because it’s so spontaneous, kids, they do different things every day and this does mean their blood readings will go up and down” (35M). Hence, parents expressed a need for more empathetic input from health professionals who had been exposed to and/or trained in the realities of living with and caring for a child with type 1 diabetes: “I’d quite happily say to [son’s name] ‘you go and stay with them for a fortnight. Get out, (laughs), see how they get on’” (34M); “sometimes I feel like saying ‘look say this to me when you’ve lived ten years with a child with diabetes. Come and speak to me then’” (28M). As well as wanting clinical advice and goals set which were realistic and tailored to their particular child, some parents indicated needing skills training themselves in order to work more collaboratively with health professionals and undertake shared decision-making, wherein:

“they say ‘you’re the experts, we’re here to advise. We know what you should be doing but, obviously, you’re living with it’ and that’s what I think it needs to be, you know, ‘have you tried doing it this way round’ or give us some sort of practical technique” (02F).

CONCLUSIONS

This study sought to understand why children with type 1 diabetes experience sub-optimal glycaemic control by drawing on parents’ experiences and views. As parents’ accounts have demonstrated, and others have also shown [13–15], managing a child’s diabetes is extremely complicated and difficult, requiring what Sullivan-Bolyai has termed “constant vigilance” [16] and also entailing remote management strategies as our findings have served to highlight. Despite their efforts to manage their child’s diabetes both directly and remotely, parents in our study described many situations and contexts which, from their perspectives, impacted on their child’s blood glucose control, but over which they could exercise little or no control. These included inclement weather and ensuing, unpredictable fluctuations in their child’s activity levels; other people’s ignorance and inappropriate feeding practices; and, physiological and social changes accompanying childhood development which, as Kushion et al. have observed, ~~and mirroring parents’ accounts,~~ can require a child’s insulin requirements to change as frequently as every two weeks [17]. In addition, and in keeping with findings from studies with adolescents and adults with diabetes [18–20], parents described needing to balance strict diabetes management against enabling their child to lead a ‘normal’ life. For all these reasons, parents discussed how keeping their child’s blood glucose levels within target ranges was often an unrealistic and unrealisable task and, hence, how they felt diabetes professionals were unduly judgemental when good control was not achieved.

In keeping with findings of other studies [4,6,13,16,21–23], worries about hypoglycaemia were a major concern for parents. Furthermore, in line with others’ speculations [7], we

found that parents do increase their child's blood glucose levels to mitigate risk of hypoglycaemia. However, given our finding that most parents operationalized two sets of blood glucose targets, with tighter targets employed when their child was in their immediate care, our study suggests that that it is not fear of hypoglycaemia in isolation which leads to decisions to raise blood glucose targets/levels. Rather, we would argue that it is parental fear *in conjunction with* other factors and considerations, including parents' lack of confidence in others, including their own child, to detect hypoglycaemia; and, the difficulties of planning for and regulating eating and physical activity when their child is not under their direct supervision.

Hence, arguably, proposed psychological interventions targeting parental fear of hypoglycaemia [21] are unlikely to be effective unless the contextual factors underlying or precipitating parents' worries and concerns are also addressed. To this end, parents may benefit from input from health professionals to train other people, such as grandparents, in diabetes management [15], to increase their confidence in others to care for their child without raising blood glucose. This could include broadening outreach work in nurseries/schools and other settings (e.g. play groups); for instance, by providing training to parents and lay volunteers so that these individuals can train up teachers and other caregivers themselves. While technologies such as closed loop systems and sensor augmented pumps are in their infancy, these might help reduce the incidence of, and, hence, parental worry about, hypoglycaemia, especially at night-time [24,25] and on other occasions when the child is not under their direct care.

Parents also highlighted unmet needs in diabetes consultations. This was not only to receive more encouragement and affirmation as others have recommended [14], but also to bring in their own expertise and experiences and to discuss these with health professionals cognizant in, and sympathetic to, difficulties of caring for a child with type 1 diabetes and keeping blood glucose levels within target ranges. It should be acknowledged that people's

recall and understanding of diabetes consultations may differ from those of health professionals [26] which may result in both parties coming out with incongruent treatment goals [27]. However, parents' accounts suggest a need for improvements in how the ways consultations are currently delivered, to aid treatment decision-making in ways which and take account of a child's everyday life and needs. To achieve this, a multi-stranded approach may be needed. In line with parents' own suggestions, this could potentially comprise experiential training for health professionals in the realities of parenting a child with type 1 diabetes and skills training for both parents and health professionals to enable them to bring their respective knowledge, experience and expertise into the consultation and undertake shared decision-making [28]. Arguably, parents might also benefit from additional training in order to gain a better understanding of the perspectives of their child's health care providers and the responsibilities these professionals feel they have to their child to optimise their glycaemic control. -Encouraging both parents to attend consultations, especially when they are separated, is also important given that separated fathers may lack familiarity with diabetes management approaches which may be detrimental to glycaemic control [29].

A key strength of this study is the involvement of an experienced qualitative researcher who is not a health professional and who conducted the interviews in very sensitive and non-judgemental ways. Because of this, very high levels of disclosure about potentially sensitive matters were achieved, enabling us to comprehensively report findings which have erstwhile been anecdotal or unrecognised. While the multi-sited recruitment strategy increases the potential generalizability of the findings, a potential limitation is the study's restriction to Scotland, where glycaemic control may be different to other countries [30]. Hence, future research, involving cross-country comparisons could be considered. In addition, and given parents' concerns about children under-reporting hypoglycaemia and not adhering to other aspects of their regimen, future work, using age appropriate methodologies, could be conducted to establish what the issues are for children and how they feel they could be better supported to improve their blood glucose control.

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References

1. IDF. Diabetes in children: epidemiology. *Pediatr Diabetes* 2007; 8(suppl 8): 10–18.
2. Scottish Study Group for the Care of the Young with Diabetes. A longitudinal observational study of insulin therapy and glycaemic control in Scottish children with Type 1 diabetes: DIABAUD 3. *Diabet Med* 2006; 23: 1216–1221
3. National Paediatric Diabetes Audit Report 2011-2012.
<http://www.rcpch.ac.uk/system/files/protected/page/NPDA%20report%202011-12%20high%20res%20FINAL.pdf>
4. Haugstvedt A, Wentzel-Larsen T, Graue M, Sovik O, Rokne B. Fear of hypoglycaemia in mothers and fathers of children with type I diabetes is associated with poor glycaemic control and parental emotional distress: a population-based study. *Diabet Med* 2010; 27: 72–78.
5. Patton SR, Dolan LM, Henry R, Powers SW. Parental fear of hypoglycaemia: young children treated with continuous subcutaneous insulin infusion. *Pediatr Diabetes* 2007; 8: 362–368.
6. Monaghan MC, Hilliard ME, Cogen FR, Streisand R. Nighttime caregiving behaviors among parents of young children with type I diabetes: associations with illness characteristics and parent functioning. *Fam Syst Health* 2009; 27: 28–38.
7. Barnard K, Thomas S, Royle P, Noyes K, Waugh N. Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review, *BMC Pediatr* 2010; 10: 50.

8. Britten N, Jones R, Murphy E, Stacy R. Qualitative research methods in general practice, *Fam Pract* 1995; 12: 104–114.
9. Pope C, Mays N. Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research, *BMJ* 1995; 311(6996): 42.
10. Glaser B, Strauss A. *The Discovery of Grounded Theory*. Chicago: Aldine Pub. Co., 1967.
11. Strauss A. Corbin, J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. London: Sage, 1990.
12. Rankin D, Harden J, Waugh N, Noyes K, Barnard K, Lawton J. Parents' information and support needs when their child is diagnosed with type 1 diabetes: a qualitative study. In press. *Health Expectations*.
13. Lowes L, Lyne P, Gregory JW. Childhood diabetes: parents' experience of home management and the first year following diagnosis. *Diabetic Med* 2004; 21: 531–538
14. Sullivan-Bolyai S; Knafk K, Deatrick J, Grey M. Maternal management behaviours for young children with type 1 diabetes. *MCN-Am J Matern-Chil* 2003b; 28: 160–166.
15. Hatton DL, Canam C, Thorne S, Hughes AM. Parent's perceptions for an infant or toddler with diabetes. *J Adv Nurs* 1995; 22: 569–577.

16. Sullivan-Bolyai S, Deatrack J, Gruppuso P, Tamborlane W, Grey M. Constant vigilance: mothers' work parenting young children with type I diabetes. *J Pediatr Nurs* 2003a; 18: 21-9.
17. Kushion W, Salisbury PJ, Seitz KW, Wilson BE. Issues in the care of infants and toddlers with insulin-dependent diabetes mellitus. *Diabetes Educator* 1991; 72: 107–110.
18. Balffe M. The body projects of University Students with type 1 diabetes. *Qual Health Res* 2009; 19: 128–139.
19. Ingadottir B. To discipline a “dog”: the essential structure of mastering diabetes. *Qual Health Res* 2008; 18: 606–619.
20. Paterson BL, Thorne S, Dewis, M. Adapting to and Managing Diabetes. *J Nurs Scholarship* 1998; 30: 57–62.
21. Grey M. Coping and Psychosocial adjustment in mothers of young children with type 1 diabetes. *Child Health Care* 2009; 38: 91–106.
22. Patton SR, Dolan LM, Henry R, Powers SW. Parental fear of hypoglycaemia: young children treated with continuous subcutaneous insulin infusion. *Pediatr Diabetes* 2007; 8: 362–368.
23. Sullivan-Bolyai S, Deatrack J, Grupusso P, Tamborlane W, Grey M. Mothers' experiences raising young children with type 1 diabetes. *J Spec Pediatr Nurs* 2002; 7: 93–103.

24. Barnard KD, Wysocki T, Allen JM, et al. Closing the Loop Overnight at Home Setting: Psychosocial Impact for Adolescents with Type 1 Diabetes and their Parents. *BMJ Open Diabetes Research & Care* 2014; 2: e000025.
25. Choudary P. Insulin pump therapy with automated insulin suspension: toward freedom from nocturnal hypoglycaemia. *J Amer Med Assoc* 2013; 310: 1235–1236.
26. Parkin T, Skinner TC. Discrepancies between patient and professionals recall and perception of an outpatient consultation. *Diabet Med* 2003; 20: 909–914.
27. Woodcock A, Kinmonth AL. Patient concerns in their first year with type 2 diabetes: patient and practice nurse views. *Patient Educ Couns.* 2001; 42: 257-70.
28. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997; 44: 681–692.
29. Thompson SJ, Auslander WF, White NH. Comparison of Single-Mother and Two-Parent Families on Metabolic Control of Children With Diabetes. *Diabetes Care* 2001; 2: 234-236.
30. Danne T, Mortensen HB, Hougaard P, et al for the Hvidøre Study Group on Childhood Diabetes. Persistent differences among the centre over 3 years in Glycemic control and hypoglycaemia in a Study of 3805 Children and Adolescents With Type 1 Diabetes From the Hvidøre Study Group. *Diabetes Care* 2001; 24: 1324-1347.

Table 1: Demographic characteristics of interview participants and their children

Characteristic	N	%	Mean \pm SD & range
<u>Parents (n=54)*</u>			
Female (mothers)	38	70.4	
Age - All parents (Years)			40.6 \pm 6.1, range 25–51
Mothers Age (Years)			40.0 \pm 5.6, range 25–51
Fathers Age (years)			42.1 \pm 7.0, range 27–51
Biological parents living together (data from 40 interviews)	28	70.0	
Current employment status			
Full-time	19	35.2	
Part-time	18	33.3	
Full-time carer	7	13.0	
Not working	9	16.7	
In education	1	1.8	
Occupation			
professional	9	16.7	
semi-skilled	12	22.2	
unskilled	17	31.5	
full-time carer / not working	16	29.6	
Education – (those with degrees)	15	27.8	
<u>Children (n=41)**</u>			
Female	17	41.5	
Age – all children			8.4 \pm 2.5, range 2–12
Female age at time of interview (Years)			9.0 \pm 2.2, range 5–12
Male age at time of interview (Years)			8.0 \pm 2.7, range 2–12

Female age at diagnosis (Years)			5.2 ± 2.1, range 3–10
Male age at diagnosis (Years)			3.6 ± 2.3, range 1–8
Diabetes duration – all children (Years since diagnosis)			4.1 ± 2.9, range 1–11
Regimen (at time of interview)			
Basal Bolus	26	63.4	
Mixed-use insulin	2	4.9	
CSII	13	31.7	
HbA1c – all children (IFCC: mmol/mol; NGSP: %)			68 ± 12.3; 8.4 ± 1.1

*A total of 40 interviews were conducted. Of these, 24 interviews were with mothers only, 2 with fathers only and 14 were joint interviews with both mothers and fathers.

** Details of 41 children are provided as one set of parents cared for two children with type 1 diabetes.

Table 2 – Relevant areas explored in the interviews

- Information, education and clinical advice received since diagnosis and parents' views about these; other sources of information accessed and used by parents.
- Everyday experiences of diabetes management (parents invited to describe a typical day during the week and at the weekend); including food choices, determination and administration of insulin doses, use of blood glucose monitoring, and use of blood glucose targets during day and night.
- Involvement of others in child's diabetes care (e.g. school); perceived impact of others on blood glucose control.
- Involvement of the child in diabetes management.
- Perceptions, understandings and reasons for high and low blood glucose levels; perceived impact of blood glucose levels on child's health, wellbeing and risk of future complications.
- Attitudes towards and experiences of hypoglycaemia and hypoglycaemia prevention strategies.
- Reasons for following and not following clinical diabetes management advice and adhering to clinically recommended blood glucose targets.
- Views about current support provision and consultations and how support from health professionals and other sources could be improved.