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Running title:

Pathways to diagnosis: parents' accounts

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Pathways to diagnosis: a qualitative study of the experiences and emotional reactions of parents of children diagnosed with type 1 diabetes

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Abstract

Objective: To explore from parents' perspectives the circumstances and events which led to their child being diagnosed with type 1 diabetes (T1D). The objective was to understand reasons for delays in seeking treatment and parents' emotional reactions to diagnosis so others can be better informed and supported in future.

Methods: In-depth interviews with 54 parents of children (aged 12 years and under) with T1D. Data analysis used an inductive, thematic approach.

Results: Parents described a 'prompt' and a 'delayed' pathway to their child being diagnosed. Parents who considered the diagnosis to be 'prompt' reported how they, or other people, had recognised their child had developed symptoms of T1D which resulted in a rapid presentation to healthcare professionals. In contrast, parents who perceived their child's diagnosis to be 'delayed' did not recognise signs of T1D and attributed their child's deteriorating health to other conditions, being out of routines and/or their stage of development. These parents often only sought medical help when symptoms became extreme. All parents were distressed by their child's diagnosis; however, parents in the 'delayed' pathway expressed unresolved feelings of guilt, particularly when their child was diagnosed in diabetic ketoacidosis.

Discussion:

Parents' and other people's knowledge about T1D can affect the duration between onset of their child's symptoms and diagnosis. Campaigns to raise awareness should ensure that parents are made aware of symptoms and that T1D can develop during childhood. Healthcare professionals could discuss with parents the events preceding their child's diagnosis to better determine their emotional support needs.

Key words: type 1 diabetes mellitus; diagnosis; parents; diabetic ketoacidosis; qualitative research

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Introduction

Type 1 diabetes (T1D) is the most common long-term metabolic disorder in childhood and global incidence rates have been increasing at around 3-4% a year (1). In the UK, approximately 26,500 children have T1D (2) and the incidence of newly-diagnosed cases (24.5 – 26/100,000 children per year) is one of the highest in the world (3). Most children with T1D are diagnosed after presenting with symptoms which develop over one to two weeks and which include: polyuria, polydipsia and weight loss (4). However, a significant proportion of young children are diagnosed with concurrent diabetic ketoacidosis (DKA) (5,6), which is a leading cause of morbidity and mortality (7). This is often due to parental delays in seeking medical care when symptoms develop and health professionals' failure to diagnose the condition when a child first presents to them (8).

As various qualitative studies have highlighted, most parents report feeling shocked, unprepared, overwhelmed, out of control and/or profoundly upset at the time of their child's diagnosis (9 – 11). These observations have been supported by a review of quantitative research (12), which found that between 10% and 74% of parents experienced symptoms of psychological distress, including anxiety, stress, depression or post-traumatic stress disorder (PTSD) at the time of and soon after their child's diagnosis (13 – 15). This review also included several longitudinal studies which have shown that parents continue to experience symptoms of PTSD, anxiety and depression one year after their child's diagnosis (14,16), with a further study showing that some continue to experience chronic sorrow many years later (17).

While the psychological impact on parents is now well recognised, relatively little attention has been given to exploring parents' accounts of the events which lead up to their child's diagnosis with T1D and how these events might influence their emotional reactions to the diagnosis. When parents' pre-diagnostic accounts have been reported, the findings have tended to be brief and presented as part of their broader experiences of caring for a child with T1D (9,16,18 – 20). Furthermore, a recent

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systematic review of factors associated with DKA at diagnosis has highlighted a need for research which explores influences on parents' decisions to seek help for their child to better understand how delays to obtaining a diagnosis arise (8). To address these gaps in the literature, and as part of a broader investigation involving parents' of children (aged 12 years and under) with T1D, we used in-depth interviews to explore parents' accounts of, and views about, the circumstances and events which lead to their child's diagnosis. Our aims were to explore reasons for delays affecting a child's diagnosis and to better understand parents' emotional and psychological responses to their child's diagnosis. A key objective was to provide recommendations to reduce delays to diagnosis and to help alleviate parents' distress arising from their diagnostic experiences.

Methods

A qualitative descriptive design was employed, comprising in-depth interviews with parents of children (aged 12 years and under) who had T1D and had been diagnosed at least six months. This exploratory design enabled parents' own understandings and experiences of their child's diagnosis to be captured to be explored in depth and afforded the flexibility needed for them to raise issues they perceived as salient, including those not anticipated at the study's outset (21). A series of preparatory interviews with healthcare professionals were used to explore how services were delivered and by whom, and to contextualise and enhance interpretation of parents' accounts. The study was informed by the principles of grounded theory, entailing concurrent data collection and analysis, enabling issues and themes identified in early interviews to inform subsequent data collection (22).

Sample and recruitment

Fifty-four parents of children (aged 12 years and under) with T1D were recruited using an opt-in method from paediatric clinics in four health boards across Scotland. Purposive sampling was used to ensure diversity of parents' location, occupational status (full-time/part-time), relationship status and their child's demographic and disease characteristics (see table 1). Ethnicity was not used as a sampling

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attribute; however, one patient interviewed was Muslim. [Permission was also sought at the end of each interview to re-approach parents, if necessary, by telephone to clarify information or explore new issues to emerge during data collection/analysis.](#) Data collection was stopped when data saturation occurred; that is, when no new findings or themes were identified in any new data collected.

<<Table 1>>

Data collection

Interviews were informed by a topic guide developed in light of literature reviews, inputs from an advisory group, ~~and~~ original research questions [and material from healthcare professionals' accounts.](#) Interviews explored: parents' experiences of, and views about, events preceding their child's diagnosis; their perceptions of and responses to their child's symptoms; views about advice/support sought from healthcare services; and their experiences and emotional reactions at diagnosis [\(see table 2\).](#) To contextualise their accounts, participants were also asked about their everyday lives and other personal factors. Interviews averaged 120 minutes, were digitally recorded (with consent) and transcribed in full [by a professional transcriber to permit for](#) in-depth analysis.

<<Table 2>>

Data analysis

A thematic analysis was conducted by DR and JL who each performed their own independent analyses, reading each participant's interview in full before cross-comparing all interviews to identify continuities and differences between accounts (22). Joint thematic analysis meetings were used to compare interpretations, explore participants' underlying reasoning, resolve any differences in interpretation and reach agreement on recurrent themes and findings (22). This process informed the development of a coding framework which reflected our original research questions and emergent themes. NVivo, a qualitative software package (QSR International, Doncaster, Australia), was used to facilitate data

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coding/retrieval. Unique identifiers are used below with the letter 'M' or 'F' signifying whether the participant is a child's mother or father respectively.

Research ethics approval was granted by the South East Scotland Research Ethics Committee 01, NHS Lothian (12/SS/0071).

Results

Whether their child was diagnosed recently or several years ago, most parents spoke at length about the circumstances and events which led to this diagnosis, their own and other people's role in facilitating or delaying the diagnosis and their ensuing emotional reactions. Several parents became visibly upset during this part of the interview but all expressed a desire to continue after regaining their composure. Below, we highlight and explore two pathways described by parents by which their child came to be diagnosed with T1D – a pathway which was perceived by parents to be 'prompt' and a pathway they considered to be 'delayed'. We also explore parents' reactions to their child's diagnosis and how some in the 'delayed' group expressed longstanding and unresolved feelings of guilt about their child not having been diagnosed sooner.

Prompt pathways to diagnosis

Suspected diabetes

Around one third of parents described having known and recognised, or having received prompts from others, that symptoms such as excessive thirst and urination were indicative of T1D and how, having detected these signs in their child, they had made rapid appointments with doctors to discuss their concerns. This typically included parents who had T1D themselves, mothers who had had gestational diabetes, those working in healthcare professions who "knew what the signs of diabetes were" (0026M), and those whose family members, friends or colleagues had the disease: "my friend's husband was recently diagnosed, so I was aware of the symptoms" (0029M). In some cases, parents

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described how relatives, friends or teachers had first raised concerns about their child's condition or how their suspicions that their child had T1D had been raised because "you see it on the telly" (0010M).

As well as taking their child to the doctor in what they considered to be a timely manner, several parents also reported having presented evidence of their child's high blood glucose readings after borrowing blood glucose testing devices from other people, such as parents of children who had the condition, or by accessing this equipment at work: "I just got a [blood glucose testing] kit from my work and I came up and tested him and I knew what it was, thought it was diabetes" (009M). In the main, parents who suspected their child had symptoms of T1D presented them for diagnosis before they had developed DKA.

Delayed pathway to diagnosis

Parents' lack of knowledge of T1D and its symptoms

Virtually all parents in this group also described how their children had developed an excessive thirst or need to urinate more frequently. However, parents who perceived their child's diagnosis to have been delayed often did not seek immediate medical advice because they did not suspect that these symptoms were serious and/or indicative of T1D. Instead, parents described how symptoms were readily confused with, and attributed to, other conditions (e.g. chicken pox, urinary infection) or minor ailments (e.g. common cold): "I just thought it was a tummy bug or a virus or something" (0015M). Other parents recalled having delayed making an appointment to see a doctor because they had initially suspected that their child's symptoms signified a recovery from another illness. 0007M, for example, described attributing her son's symptoms to a recent infection and his attempt to "flush it out" by rehydrating:

"I was beginning to think, oh maybe I should be doing something about it but then, rationally, you're thinking, well he sat and ate his tea, he's not a sick child, he's doing all the normal things

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and, yes, he's getting a bit tired, yes he's drinking lots but he has had this infection, it kept coming back to that."²

Parents also described having delayed speaking with a doctor because, initially at least, their children had remained in good health despite their excessive thirst and urination: "she was fine, she wasn't ill, she didn't have a sore tummy, she had nothing, no other symptoms at all" (0018M). Instead, these parents often attributed their child's symptoms to a reaction to changes in family routines, such as a mother being pregnant or, in several cases, to being abroad on holiday during the summer when the whole family was drinking more frequently: "I kind of just put it [excessive thirst] down to the weather" (005M). Similarly, 0021M, whose family were also on holiday when symptoms first developed, attributed her six-year-old daughter's night-time bed-wetting to her being: "out of her routine and going into a big deep sleep because she had been so tired from the [children's] disco or whatever."

Symptoms are confused with normal stages of children's development

Several parents in the 'delayed' group also described how they had, initially at least, attributed symptoms such as frequent bed-wetting to their child's stage of development as children aged under 3 years had often not been toilet-trained and because at this stage in the life-course bed-wetting was not uncommon: "[Our son] had a habit of peeing the bed, he still does" (0023F). Other parents described how they had had no reason to feel alarmed because their child had a history of occasional bed-wetting, or tended to drink liquid in large quantities: "that's just a habit some kids get that they're just wanting to drink all the time and I kind of put it to one side" (0016M). Likewise, other parents highlighted how symptoms such as weight loss could be misconstrued as part of normal development. This included 0021M, whose daughter was five years old when symptoms first arose:

"I'd noticed she'd started to slim down but [daughter] was a wee bit, she wasn't chubby but I thought, 'well, she's losing all her puppy fat', but just because of the age that she was, that would have been normal."² (0021M)

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Young children's inability to communicate symptoms

Parents who considered their child's diagnosis to have been delayed reported how their appraisals of their child's health and wellbeing were also influenced by whether their young son or daughter was able to articulate and convey feelings of being unwell. For example, 006M, whose son had also begun to exhibit symptoms of thirst, described assuming, because of his age, that his symptoms were only a result of play-acting:

“he was just drinking and sleeping on the floor and we put him into bed and we'd go through at midnight and he'd have taken all his clothes off ... So we were getting cross with him because we thought he was being silly but, actually, he was feeling terrible, but he didn't know how to communicate it 'cause he was only nearly four so he didn't really have that skill to say, what was the matter.”

A child's inability to articulate feeling unwell, coupled with parents' uncertainty about symptoms of T1D, could also precipitate actions, and delays, which further exacerbated their deteriorating health. For example, 0010M, whose child was eventually admitted in DKA, spoke about her five-year-old son's inexplicable but frequent bed-wetting and how, as a consequence, she had withheld further liquid: “So the night before we took him to the doctors, I decided, right, you're not getting anything to drink after six o'clock and he was screaming for a drink but, at the time, we didn't know why”.

Tipping points

As highlighted in 0010M's account, extreme behaviours such as a child “screaming for a drink” could act as ‘tipping points’ prompting parents in the delayed group to seek help because symptoms could no longer be associated with other illnesses or normal childhood development. For example, several parents described only becoming concerned about excessive urination and bed-wetting when they discovered that their child's bed was “like a swimming pool” (0023M) or when, during car journeys,

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their child had asked to “stop for the toilet about twenty times” (0006M). Parents whose child had an excessive thirst also described only seeking medical help when their symptoms became extreme. This included 0007M who, as reported above, had initially attributed her child’s thirst to a residual infection but described how the onset of extreme symptoms had prompted her to seek emergency help for her 18-month-old son who was eventually admitted in DKA:

“Then it came to a crux, he was in the bath and he turned round on all fours and was drinking the bath water. He actually had his head in the water, drinking it. He was just so desperate.

When I took him out of the bath night, he was quite shut down, peripherally, actually, purple lips, hands, feet.”

Visits to the doctor: instances of misdiagnosis

Most parents in the ‘prompt’ pathway reported articulating concerns about their child’s symptoms to the family doctor before obtaining a rapid diagnosis and referral to hospital. However, there were a few parents who, despite making prompt appointments to discuss concerns about T1D, reported that the family doctor “didn’t see any signs of diabetes” (0020M), which delayed their child’s diagnosis until a later consultation. Parents who were uncertain about their child’s symptoms, but who made prompt appointments, also described how a GP’s failure to diagnose T1D delayed their child’s treatment.

0015M, for instance, who attributed her son’s nocturnal bed-wetting to a “stomach bug”, described how: “the doctor just thought it was a bug and it would, kind of, pass” before a second appointment a week later resulted in a referral and the correct diagnosis being made.

Several parents in the ‘delayed’ pathway also reported examples of misdiagnosis by GPs when they eventually did seek help. In these cases, a misdiagnosis could have profound consequences. This included 0001M, who had initially attributed her three year old child’s symptoms to a “viral infection” and who waited two weeks before making an appointment with a GP. Recalling how the GP failed to

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diagnose T1D, this mother described how her daughter's condition suddenly deteriorated before she was admitted to hospital in an emergency after developing DKA:

“she was peeing a lot, she'd lost weight ... but you never think type 1 diabetes. So we took her to the doctor and I think they said she was okay, it was just Calpol to give her and I brought her home and then the next day I had to phone an ambulance... she was getting worse and worse.”

Parents' emotional and psychological reactions to a child's diagnosis

Virtually all parents reported being extremely distressed when their child was diagnosed. This included those in the 'prompt' pathway, who knew about the symptoms of T1D, but who nonetheless reported being “very upset” (0003M) and shocked: “I had a fit” (0009M) when the diagnosis was confirmed. However, parents in the 'delayed' pathway, many of whom had “no history of it [diabetes]” (0004M) in their families, were often more emotionally ill-prepared at the time of diagnosis: “I collapsed at the hospital” (0001M). These parents reported being “absolutely distraught” (0029), shocked: “I just thought it wasn't the right diagnosis” (0006M) and traumatised, particularly if their child was diagnosed in DKA and thought to be “on death's door” (0001M) at the time of diagnosis: “I felt like I'd hit, you know, I'd hit a brick wall, felt like I'd been in a car crash, actually” (0007M). Furthermore, these parents often described how their lack of knowledge about T1D had left them struggling to understand their child's diagnosis.

“I didn't really know about diabetes at that time either, so I was like, when do you think we'll get home, thinking it would be a few hours later, and they're like, “oh, it's going to be quite a few days that you're going to be in here.”” (0016M)

Aside from their differing reactions to their child's diagnosis, parents in the 'delayed' pathway, in contrast to those in the 'prompt' pathway, often reported feelings of deep-rooted guilt and self-blame when they speculated about whether they could have done more to detect their child's symptoms in the weeks leading up to diagnosis: “it was the night before he turned seven that he started to, to wet

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the bed. So that was like, sort of a fortnight... I felt really guilty, you know, I said to [husband], 'oh, we should have had him at the doctor's sooner', but we didn't" (0011M)

In other examples, parents whose children were diagnosed in DKA often reported more extreme feelings of guilt and self-reproach "was I not a caring enough parent?" (0017M) because "I don't think we picked it up early enough, she was very, very, very ill when we took her in. It haunts me" (0017M). Furthermore, parents whose children were diagnosed in DKA described how, over the years, they had relived the events leading up to their child's diagnosis and continued to admonish themselves for not having detected symptoms any earlier: "Looking back, if we had the slightest idea we could, we could have spotted something sooner, but we didn't..." (0002F). This also included 0019M, who continued to express regret for her perceived failure to detect her daughter's symptoms more than six years ago:

"looking back, all the signs were there...I remember she was going to [the park] ... and she said, "will there be toilets there?" and then, the week before she was diagnosed, ... she looked terrible, she was pale and she was gaunt and she said, "[friend's mother] wouldn't give me a drink, I kept asking for a drink". So that was another sign".

Discussion

This study has identified two main 'pathways' which encapsulate parents' accounts of how their child came to be diagnosed with T1D – a 'prompt' pathway and a 'delayed' pathway. Our findings have also shown how parents' and GPs' reactions and responses to a child's symptoms can affect the duration of time which can elapse until a diagnosis is made. We have also illustrated how parents who considered their child's diagnosis to have been delayed can experience entrenched and unresolved feelings of guilt and self-recrimination about whether they could have done more to detect symptoms, particularly when their child was eventually diagnosed in DKA.

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In keeping with the findings of other studies (e.g. 9,10,18,19), we have shown how some parents who perceived that their child's diagnosis was delayed were initially confused by and misattributed symptoms such as excessive thirst and urination to other childhood ailments and changes in routine. We have also shown how some family doctors themselves failed to recognise symptoms of T1D when a child presented to them. Hence, these findings help to illuminate why a significant number of children, in particular those aged 2 years or under, may also be diagnosed in DKA (5,6). Specifically, we have seen how, in the case of particularly young children, parents often delayed presenting their child for diagnosis because they had considered changes in their child's bodily states to be a normal part of childhood development or because very young children had been unable to communicate feelings of ill-health.

As our analysis of the two groups has highlighted, it is parents', GPs' and other people's knowledge about T1D and its symptoms which are key to a child being rapidly diagnosed. This finding underscores the potential benefits of national campaigns to raise awareness, such as the "4T's" promotion run by Diabetes UK and JDRF (23) advising parents to look out for symptoms such as a child going to the "Toilet" more frequently, being very "Thirsty", feeling more "Tired" than usual or looking "Thinner" than normal. However, while such campaigns aim to promote better knowledge of signs of T1D, we would recommend that parents and people who care for children should be made aware that the disease commonly develops during childhood in order to help limit the situation arising where symptoms are confused with other childhood ailments.

We have also shown how parents experience emotional reactions at the time of their child's diagnosis and how many also express long-standing, deep-rooted and pervasive feelings of guilt about whether they could have done more to recognise and respond to symptoms earlier. These findings resonate with those from a qualitative study conducted by Peel et al (24) which involved adults newly diagnosed with type 2 diabetes (T2D) and which also identified several 'routes' to diagnosis. In their study, Peel et al

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explored how adult patients' 'route' to diagnosis affected their subsequent information and support needs, with patients who did not suspect they had developed T2D experiencing the most varied and extreme emotional reactions. These observations led the authors to recommend that healthcare professionals should be sensitive to the 'routes' by which patients come to be diagnosed and to tailor information and support accordingly. In line with Peel et al's recommendations, we would suggest that healthcare professionals could place greater emphasis on exploring with parents the circumstances leading up to their child's diagnosis in order to ensure they receive appropriate and tailored emotional support.

Parents' extreme reactions of shock and their accounts of longstanding, unresolved feelings of guilt offer insight into why individuals can become psychologically distressed by their child's diagnosis (13 – 16). Such distress, as Whittemore et al have shown, can also have negative effects on parents' ability to manage their child's diabetes (12). Hence, to identify those who might need additional support to counter stress, anxiety and depression and to help parents to better manage their child's diabetes, our data suggests, in line with previous recommendations, that all parents be screened for psychological distress when their child is diagnosed and at regular intervals thereafter (12). In addition, our findings suggest that parents of children diagnosed in DKA may be at particularly high risk of psychological distress and may need to be screened most regularly. Alongside high-risk groups, all parents conveyed feelings of upset and distress when their child was diagnosed. Hence, more broadly, and similar to recommendations made in other studies, (e.g. 9,10,19) our findings highlight a need for all parents to be given emotional and psychological support when their child is diagnosed with T1D.

Strengths and limitations

A key strength was our use of an exploratory design and our decision to recruit parents whose children were of different ages as this has enabled us to highlight and explore how a child's age can affect parents' ability to detect and respond to symptoms. A limitation is our use of a mostly White, ethnically

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homogenous sample, which potentially limits the generalisability of the findings. A further potential limitation is our reliance on parents' accounts. Future work could explore healthcare professionals' accounts as several doctors were implicated by parents in delays to a child being diagnosed. Furthermore, by virtue of participants retrospectively narrating the events leading up to their child's diagnosis, their accounts may have been subject to recall bias and/or narrative reconstruction (25) in order to present themselves as caring and responsible parents. While this cannot be discounted, it seems unlikely, given that many parents in the 'delayed' group seemed to use the interview situation to admonish themselves for their perceived failure to spot symptoms and take prompt action.

Conflict of interest

The authors declare that they have no conflict of interest.

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Table 1: Demographic characteristics of interview participants and their children

Characteristic	N	%	Mean ± SD & range
<u>Parents (n=54)*</u>			
Female (mothers)	38	70.4	
Age - All parents (Years)			40.6 ± 6.1, range 25–51
Mothers Age (Years)			40.0 ± 5.6, range 25–51
Fathers Age (years)			42.1 ± 7.0, range 27–51
Married / living with partner	46	85.2	
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 caregiver / 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 ± 2.5, range 2–12
Female age at time of interview (Years)			9.0 ± 2.2, range 5–12
Male age at time of interview (Years)			8.0 ± 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

* 40 interviews were conducted, including 24 with mothers, 2 with fathers and 14 joint interviews (mother and father).

** Details of 41 children are provided as one set of parents cared for two children with T1D.

Pathways to diagnosis

Table 2: Topic guide questions on parents' experiences of their child's diagnosis

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- Can you tell me what happened and what events lead up to your child being diagnosed with type 1 diabetes? (Probe: child's age at diagnosis, current age, child's symptoms or ill-health and parents' views about and responses to these symptoms, how parents came to seek help, what happened when help was sought, how parents came to be informed about their child's diagnosis).
 - What support did you seek from healthcare professionals? (Probe: who did they seek help from, who made the diagnosis, how long did it take to obtain a diagnosis, views about the support they received?)
 - What did you know about type 1 diabetes at the time your child was diagnosed?
 - How did you and other family members react at the time to news of the diagnosis?
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