

Parental responses to a diagnosis of Type 1 diabetes

When a child is diagnosed with Type 1 diabetes, their parents may experience long-lasting anguish and unresolved guilt.

Dr David Rankin and **Professor Julia Lawton**, University of Edinburgh, present their recent research on this issue, and consider how healthcare professionals can help

Children who develop Type 1 diabetes are usually diagnosed after presenting with symptoms such as excessive thirst, frequent urination and weight loss. However, a significant proportion of children are diagnosed with concurrent diabetic ketoacidosis (DKA), often because parents delay seeking medical advice and/or because healthcare professionals find it difficult to diagnose the condition.

In 2012, we undertook an interview study to explore the experiences of parents who care for a child (aged 12 years and under) with Type 1 diabetes to better understand the obstacles and challenges they encountered when trying to manage their child's condition¹⁻⁶. Following on from this, in 2015, we conducted focus groups with parents of children with Type 1 diabetes to discuss how people in their position could be better supported to care for their child and improve their glycaemic control.

While we had not intended it to be an explicit focus of either study, most of the parents we spoke to wanted, needed and, in some cases, expected, to talk about their experiences of their child's diagnosis. Not only did parents provide very rich and often lengthy accounts of what had clearly been a very difficult and distressing time for them, many also indicated that they still had unresolved feelings of guilt. Hence, in this article we share these findings in order to raise awareness among

Shocking news – diagnosis has lasting impact

healthcare professionals of parents' unmet needs for support following their child's diagnosis.

To do this, we begin by describing parents' accounts of events leading up to their child's diagnosis, then report the emotional impact the diagnosis had on them, both at the time and subsequently. We conclude by illustrating the challenges parents encountered when trying to assimilate information about diabetes management in the aftermath of the diagnosis^{1,2}.

Delays to diagnosis

Our interviews and focus groups with parents were often very challenging, with many people becoming visibly upset when they began to recall events surrounding their child's diagnosis. Irrespective of whether their child had been diagnosed recently, or several years ago, most parents gave detailed and often highly emotive accounts of diagnosis and its impacts.

Only a few parents told us how they or other people (eg family members or teachers) had suspected their child's symptoms were indicative of Type 1 diabetes before arranging an appointment with the doctor and receiving a prompt diagnosis. Instead, most parents described how their child was only diagnosed after a delay, in some cases more than a month after symptoms had first been detected.

Confusion and lack of knowledge

All parents who considered that their child had been diagnosed after a delay described how their son or daughter had developed symptoms, such as an extreme thirst and/or need to visit the toilet more frequently. However, many of these parents also told us how they had not initially contacted their child's GP because they did not consider these symptoms to be serious or they did not know these were indicative of Type 1 diabetes. Typically, these parents described having attributed such symptoms to other less serious conditions or minor ailments, such as a common cold.

Others talked about having delayed speaking to a healthcare professional because, when symptoms first developed, their child had remained healthy despite their excessive thirst and urination. This included some parents who recalled being confused by their child's symptoms and having suspected that they were a reaction to a

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change in routines. For example, one mother described paying little attention to her child's excessive thirst when abroad in a hot country because the whole family was drinking more frequently. Another parent attributed her daughter's nocturnal bed-wetting to exhaustion, following a busy day playing with friends, which meant she had not woken up to go to the toilet.

Attributing symptoms in very young children

Parents of very young children reported particular difficulties understanding and interpreting symptoms. Such parents described having confused symptoms, such as nocturnal bed-wetting and weight loss, with their child's normal stage of development, as children under the age of three years often had not been toilet-trained, or because loss of appetite followed by a drop in weight was not uncommon if their child had a cold. Parents of some older children also told us they had not been concerned when symptoms had first developed, particularly if their child had a history of occasional bed-wetting.

Of course, very young children are unable to articulate feelings of being unwell. Therefore, parents who delayed seeking help often described only making an appointment with their child's GP after their child had begun to exhibit extreme behaviours and when their symptoms could no longer be explained by other childhood illnesses.

In a particularly distressing account, one mother told us how, at first, she had suspected her 18-month-old son's excessive thirst had been indicative of his need to rehydrate following a urine infection. However, after waiting a further week, she described finding her son desperately drinking his own bathwater, followed by a rapid deterioration in his condition before he was rushed to hospital where he was admitted in a state of DKA.



Diabetes UK's 4Ts campaign

The experiences described in this article underline why Diabetes UK launched its 4 Ts campaign in 2012. The aim of the campaign is to raise awareness of the most common symptoms of Type 1 diabetes (the 4 Ts – Toilet, Thirsty, Tired and Thinner). The 4 Ts campaign has already had an impact and continues to do so. For instance, a paediatric diabetes specialist nurse in North Lincolnshire set out to increase awareness of the 4 Ts, and took campaign posters and flyers to schools, parents, libraries, clinics and GP surgeries across the region. In just 12 months, she said that the number of children with Type 1 diabetes admitted to a North Lincolnshire hospital with DKA more than halved. For more information and to download healthcare professional resources go to www.diabetes.org.uk/the4Ts



Raising awareness of childhood diabetes



Misdiagnosis

Conversely, a significant number of parents described how concerns about their child's symptoms had prompted them to make a rapid appointment with the GP, only to receive advice to treat a viral infection or stomach bug. Some told us how repeat, or multiple, appointments, had been necessary before the correct diagnosis was finally made.

Some also told us how initial misdiagnosis had had serious consequences for their child. In one such case, a mother who had initially attributed her child's symptoms to a viral infection waited two weeks before making an appointment with the doctor. After being sent home with advice to treat an infection, she described having to call an ambulance in an emergency after her daughter had developed DKA.

Unresolved guilt

All parents talked about being extremely shocked when they were informed about their child's diagnosis. However, parents of children whose diagnosis had been delayed, many of whom knew little

about Type 1 diabetes, described feeling distraught and traumatised, particularly if their child had been diagnosed with concurrent DKA. Indeed, many of these parents expressed long-lasting and deep-rooted feelings of guilt about whether they could have done more to detect symptoms sooner. Most worryingly, some parents told us how they continued to relive events leading up to their child's diagnosis – up to six years later in one instance – and how they experienced persistent feelings of regret and self-chastisement because they had not responded to their child's symptoms any earlier.

Many of the people we interviewed also described having been so upset by their child's diagnosis that they had been unable to comprehend or assimilate clinical advice about diabetes management provided to them in hospital. This included parents who described feeling extremely anxious because they had feared that their child might die. Perhaps unsurprisingly, many of these parents told us that they had returned home feeling ill-prepared and struggling to care for their child.

Recalling these experiences, several people suggested that more reassurance and emotional support could be given upfront to help allay such fears and to help better prepare parents to absorb clinical advice given about diabetes management before they began to care for their child at home.

Recommendations

In sharing these findings with you, we hope to contribute to campaigns which aim to raise awareness about symptoms of Type 1 diabetes (see 4 Ts box, page 27), and to highlight how the condition often develops during childhood. This should lessen the risk of symptoms being confused with other common childhood conditions and ailments.

We suggest that healthcare professionals might use consultations to explore with parents the circumstances leading up to their child's diagnosis, to determine their need for emotional and psychological support. We would also encourage healthcare professionals to approach parents soon after diagnosis to discuss and address their concerns about Type 1 diabetes. As part of these



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Help parents support their child with Type 1

conversations, healthcare professionals could also offer parents emotional support and reassurance that they are not to blame in instances when their

child’s diagnosis was delayed, before providing them with education and advice about managing diabetes in home settings.

Parents speak out

ADRIENNE BURTON, Joint Chair of The Families with Diabetes National Network, reports on a recent survey of 900 parents about psychological support for themselves when their child was diagnosed with Type 1 diabetes. Only 136 had had a meeting with the team psychologist at diagnosis or just after. Of these, 73 found the meeting really helpful. Among those not offered psychological support, 80 per cent said they would have liked to have been offered it. The high percentage is because parents know, with hindsight, what a huge impact a Type 1 diagnosis has on the whole family.

The needs of parents seem to be forgotten when their child is diagnosed. When asked: 'Have you asked for psychological support for yourself?' 102 respondents said they had, of whom 63 had it agreed and 39 did not. The Network received many comments on this issue, such as: 'The message was never passed on' and 'It was not needed apparently. I just had to go and source it myself if I wanted to'. That there is a great need for more support for parents is clear from the response to the final question, about whether their anxiety levels had increased following diagnosis. Well over half of the parents said that it had.

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www.familieswithdiabetes.co.uk