

Helping caregivers optimise glycaemic control in children with type 1 diabetes: A qualitative study exploring parents' experiences and views

David Rankin, Julia Lawton

Children with type 1 diabetes aged under 12 years often experience suboptimal blood glucose control. The parents of children in this age group assume much of the responsibility for undertaking and supervising diabetes-related tasks; however, little attention has been paid to how they manage their child's diabetes or can be better supported in caring for their child and improving their blood glucose control. This overview summarises key findings and implications for health professionals arising from an exploratory qualitative study undertaken in Scotland, involving the parents of children with type 1 diabetes. This includes identification of factors and considerations that influence and inform parents' adherence to treatment advice, and ways in which parents could be better supported at, and soon after, their child's diagnosis, to manage diabetes effectively in the home setting and during paediatric diabetes consultations.

Many young children with type 1 diabetes experience suboptimal glycaemic control. Among those aged 12 years and under, parents assume much of the responsibility for managing diabetes and attaining blood glucose levels within clinically recommended target ranges.

This article presents an overview of published findings and their implications for health professionals, which arose from a recent interview study that explored parents' experiences of caring for a young child (≤ 12 years) with type 1 diabetes (Rankin et al, 2014a; 2014b; 2015; Lawton et al, 2015a; 2015b). The objective of the study was to identify ways of providing better support for parents to help them manage their child's diabetes and improve their glycaemic control.

Study origins

The interview study was developed in response to an approach from the authors' colleagues who had recently completed a systematic review of

studies evaluating fear of hypoglycaemia among the parents of young children with type 1 diabetes and its impact on their child's blood glucose control (Barnard et al, 2010). Following completion of the review, Barnard et al (2010) concluded that, while fear of hypoglycaemia is common among parents, there is a lack of evidence that it directly leads to parents allowing their child's blood glucose levels to run higher than clinically recommended to avoid hypoglycaemia. Barnard et al (2010) therefore recommended that open-ended, exploratory research be conducted with parents to better understand their reasons for allowing high blood glucose levels, in order to inform future provision of support for these individuals.

This research has recently been completed and the findings published in five papers (Rankin et al, 2014a; 2014b; 2015; Lawton et al, 2015a; 2015b). This article summarises the key findings of four of the papers and highlights the implications, which are especially relevant to health professionals

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Article points

1. This article summarises findings and implications for health professionals from an interview study that explored parents' perspectives to ascertain why children with type 1 diabetes experience suboptimal glycaemic control.
2. Parents described needing more support at diagnosis and when they started to manage their child's diabetes at home.
3. Parental fear of hypoglycaemia in conjunction with other factors and considerations leads parents to elevate their child's blood glucose levels.
4. Features of the clinic could hinder communication, understanding and knowledge acquisition during paediatric consultations.

Key words

- Glycaemic control
- Paediatric consultations
- Parents
- Qualitative research
- Type 1 diabetes

David Rankin is a Research Fellow and Julia Lawton is Professor of Health and Social Science, Centre for Population Health Sciences, University of Edinburgh.

Page points

1. While all parents talked about feeling shocked and extremely distressed when told their child had diabetes, many of those who had delayed seeking help described long-standing, pervasive and unresolved feelings of guilt.
2. This included parents interviewed up to 6 years after their child was diagnosed with diabetes, who described how they still replayed events leading up to the diagnosis and speculated endlessly about whether they could have done more to detect the symptoms sooner.
3. It is suggested that healthcare professionals could take time during consultations to explore parents' accounts of the events leading up to their child's diagnosis. This could be used to identify individuals who might benefit from additional help to counter the stress and anxiety arising from their experiences of diagnosis and provide reassurance that feelings of guilt are not unusual.

involved in paediatric diabetes care. The fifth paper explores parents' experiences and views about using an insulin pump to manage their child's diabetes (Rankin et al, 2015).

Summary of methods

The methods are reported in full elsewhere (Rankin et al, 2014a; 2014b; 2015; Lawton et al, 2015a; 2015b). In brief, 54 parents (38 mothers, 16 fathers) were recruited from four paediatric diabetes centres across Scotland. All interviews were conducted by DR in the parents' own homes using a topic guide. Interviews averaged 2 hours and were staggered so that data collection and analysis took place concurrently, allowing issues that had been identified in early interviews to be explored in more depth in later ones (Corbin and Strauss, 2015).

The authors each performed an independent thematic analysis using the method of constant comparison (Corbin and Strauss, 2015) before meeting to compare interpretations, reach agreement on key themes and develop a coding framework. Data were coded and retrieved using NVivo 9 (QSR International).

Findings

Virtually all parents described their interview as having provided them with a rare opportunity to talk about their experiences of caring for a child with type 1 diabetes, the challenges they encountered, and their concerns about other people's ability to look after their child.

This overview begins by describing parents' experiences and emotional reactions at the time their child was diagnosed, and their need for post-diagnostic support. It then highlights the challenges that parents encountered when managing their child's diabetes and ways in which they felt they could be better supported to optimise their child's glycaemic control. Finally, it looks at parents' experiences of their child's diabetes consultations and how these could be adapted to aid communication, understanding and knowledge retention.

Parents' experiences of diagnosis and need for support

The interview study did not initially set out to explore parents' experiences of diagnosis. However, during the initial interviews, when parents were

asked about their child's history of diabetes, many spoke spontaneously, and often at considerable length and with great anguish, about their experiences of and emotional reactions to their child's diagnosis. In response, the topic guide was adapted to allow these experiences and parents' need for post-diagnostic support to become a key part of the investigation.

Findings revealed that, while some parents had had straightforward experiences when their child was diagnosed with diabetes, there was a substantial number who had not. The latter group spoke about misunderstanding or being confused by their child's symptoms of excessive thirst/urination and how they had discounted or misattributed these to other less serious childhood ailments, changes in routines, or normal stages of childhood development. In often harrowing accounts, parents discussed how, as a consequence, they had delayed seeking advice from their doctor, often to the point when a crisis situation had been reached, such as when their child was admitted to hospital having developed diabetic ketoacidosis (Rankin et al, 2014a).

While all parents talked about feeling shocked and extremely distressed when told their child had diabetes, many of those who had delayed seeking help described long-standing, pervasive and unresolved feelings of guilt. Most worryingly, this included parents interviewed up to 6 years after their child was diagnosed with diabetes, who described how they still replayed events leading up to the diagnosis and speculated endlessly about whether they could have done more to detect the symptoms sooner (Rankin et al, 2014a).

While these findings highlight the importance of awareness-raising campaigns, the study authors also recognise that there are few "easy" solutions to address delays affecting the diagnosis of diabetes in young children. However, the findings suggest that parents would benefit from more emotional and psychological support around the time of their child's diagnosis and thereafter. In particular, and to address the needs of those with deep-rooted feelings of guilt, it is recommended that healthcare professionals could take time during consultations to explore parents' accounts of the events leading up to their child's diagnosis. This could be used to identify individuals who might benefit from additional help to counter the stress and anxiety

arising from their experiences of diagnosis, and to provide reassurance that feelings of guilt are not unusual (Rankin et al, 2014a).

Post-diagnostic information and support

As well as sharing their feelings of distress and shock when their child was diagnosed, parents described having felt too distraught to assimilate what many considered to be an overwhelming amount of information about diabetes management in the aftermath of diagnosis. While all parents recognised that they needed regimen-specific information before they could begin caring for their child at home, they also reported needing, in the first instance, reassurance and emotional support from health professionals to address visceral fears that their child might die. Parents suggested that such support might have helped to better prepare them to absorb practical advice thereafter (Rankin et al, 2014b).

Most parents also talked about returning home with their child, feeling unprepared for how life would change and needing more emotional and practical support to manage their child's diabetes at home. While a few parents did receive emotional support from their child's diabetes team, most reported not seeking help because they were worried about burdening staff or how they might be perceived if they admitted to being unable to cope.

All parents praised the availability and quality of clinical support; however, many commented that they would have liked clinicians to have initiated contact with them, either by phone or by making home visits. This included parents who talked about needing emotional support and practical advice tailored to their family circumstances, to help them integrate skills such as carbohydrate counting and insulin regimens into everyday life (Rankin et al, 2014b).

In light of these findings it is recommended that health professionals speak to parents soon after diagnosis and offer reassurance about their child's condition to enable them to better assimilate knowledge about diabetes management practices thereafter.

It is also recommended that health professionals initiate contact with parents in the initial weeks following diagnosis, either by phone or by arranging home visits, to explore their need for emotional

support and, if necessary, to offer practical advice that takes account of their unique family arrangements (Rankin et al, 2014b).

The challenges of optimising glycaemic control

Despite initial difficulties in assimilating instruction about diabetes management after diagnosis, all parents described how, over time, they had become very aware of the importance of maintaining their child's blood glucose levels within clinically recommended target ranges. However, parents also shared their worries about finding their child unconscious, or recounted traumatic experiences when their child had collapsed as a result of hypoglycaemia, which left them feeling reluctant and unwilling to keep their child's blood glucose levels consistently within these ranges.

As well as worrying about their child's and other caregivers' ability to detect symptoms of hypoglycaemia, parents highlighted the challenges of adhering to clinical advice when their child was cared for by others, including in school. For example, parents recounted difficulties arising from changes in the weather, which meant they could not predict their child's level of physical activity. Others told how their efforts to ensure that the correct dose of insulin was administered by providing carbohydrate-counted packed lunches or using school menus were often undermined by their child swapping food with friends, items in the canteen running out, or a lack of availability of staff to monitor their child's food consumption (Lawton et al, 2015a).

In often candid accounts, parents recounted how they addressed these concerns by using two sets of blood glucose targets. Tighter, clinically recommended targets were used when parents could directly supervise their child and monitor their food consumption and physical activity in order to calculate insulin doses. In contrast, parents described using looser, higher targets, often as a safety measure, when their child was not under their direct supervision and when they lacked confidence in their child and other caregivers (e.g. at school/nursery) to detect and treat hypoglycaemia. In addition, parents described worrying about the psychological impact of diabetes on their child and how they tried to allow them to have a "normal"

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Page points

1. Many parents were concerned that consultants had unrealistic expectations of their ability to manage diabetes and based treatment decisions on HbA_{1c} readings, growth charts and algorithms, rather than tailoring these to each child.
2. Many parents reported that they would like more empathic support from health professionals who better understood the real-life challenges of caring for a child with diabetes.
3. Some parents highlighted their own need for skills training to enable them to work more collaboratively with health professionals.
4. Parents often described feeling very anxious going into consultations because of worries that they would be judged if their child's HbA_{1c} reading had not improved; others reported that these anxieties could affect their concentration and ability to assimilate information during consultations.

childhood by relaxing food choices at weekends and parties, or by increasing carbohydrate intake to allow them to run around and play with friends without risk of hypoglycaemia.

The findings illustrate that it is not fear of hypoglycaemia in isolation that leads parents to elevate or allow high blood glucose levels, but rather fear of hypoglycaemia in conjunction with other factors and considerations, most notably parents' lack of confidence in others (including their own child) to detect and manage hypoglycaemia. This prompted the recommendation that health professionals could consider providing training in diabetes management to other caregivers (e.g. family, staff in nurseries and schools), or training to parents to cascade this advice/instruction themselves.

In addition, it is recommended that health professionals could consider using new technologies such as continuous glucose monitoring and sensor-augmented pumps to reduce the incidence of, and parents' concerns about, hypoglycaemia when their child is not under their direct care (Lawton et al, 2015a).

Experiences of consultations and suggested improvements

As well as speaking frankly about the challenges of adhering to clinically recommended blood glucose targets, parents spoke at length about the difficulties encountered during their child's consultations. Many parents were concerned that consultants had unrealistic expectations of their ability to manage diabetes and based treatment decisions on HbA_{1c} readings, growth charts and algorithms, rather than tailoring these to each child (Lawton et al, 2015a). Indeed, many parents reported that they would like more empathic support from health professionals who better understood the real-life challenges of caring for a child with diabetes. Some parents also highlighted their own need for skills training to enable them to work more collaboratively with health professionals (Lawton et al, 2015a).

Interviews with parents also revealed how contextual and structural features could affect communication and knowledge acquisition during consultations (Lawton et al, 2015b). For example, parents often described feeling very anxious going into consultations because of worries that they

would be judged if their child's HbA_{1c} reading had not improved. As many parents reported, these anxieties could affect their concentration and ability to assimilate information during consultations.

Some parents also described being distracted during consultations by young children who demanded their attention, or being reluctant to discuss matters related to future complications in front of an older child who understood, and might worry about, the implications of having diabetes.

Parents also described how the size of the clinic, lack of staff continuity and concerns about clinics being too busy could all affect whether they had opportunities to ask questions, retain information/advice or seek help for themselves.

To improve consultation experiences, it is suggested that a range of options might be considered (Lawton et al, 2015a). These include:

- Offering consultants experiential training about the everyday reality of caring for a child with diabetes.
- Skills training for both health professionals and parents so that each could bring their own skills and knowledge to the consultation to aid shared decision-making.

The study authors also recommend several ways to address structural and contextual features affecting parents' understanding and recall of information during consultations (Lawton et al, 2015b). These include:

- Sending parents written summaries of consultations to highlight what was discussed and the key decisions reached.
- Providing parents with opportunities to have a child absent for part of the consultation.
- Reassuring parents that additional time is available outside clinic for all issues to be raised.
- Advising parents that systems are in place to record and share outcomes of consultations between health professionals to ensure continuity of care.
- Encouraging health professionals to deliver test results in a sensitive manner to help parents better focus on treatment decisions made during the consultation.

Implications for health professionals

The key recommendations from the study are summarised below. These could be considered for

use by health professionals who provide care for children with type 1 diabetes and their parents.

- Health professionals could explore with parents the circumstances surrounding their child's diagnosis to identify unmet needs for emotional support, particularly among those whose children were diagnosed after a delay and who may be at high risk of psychological distress (Rankin et al, 2014a).
- When a child is newly diagnosed with diabetes, health professionals could begin by reassuring parents about their child's condition, in order to better prepare them to assimilate the regimen-specific information required to manage their child's diabetes at home (Rankin et al, 2014b).
- Given that some parents are reluctant to seek or access help, health professionals could schedule home visits, or initiate telephone calls, to explore parents' need for practical and emotional support in the first few weeks after their child has been diagnosed (Rankin et al, 2014b).
- To improve parents' confidence in others' ability to care for their child, health professionals could provide training in diabetes management to other carers and/or equip parents with the relevant skills to enable them to cascade this information (Lawton et al, 2015a).
- Treatment decision-making could potentially be improved to take more account of a child's everyday life by:
 - (a) providing health professionals with training to enhance their understanding of the realities of parenting a child with diabetes
 - (b) offering skills training to parents to enable them to share their knowledge and expertise with their child's clinicians.
- Health professionals could help parents make more effective use of consultations and improve their child's clinical outcomes by:
 - (a) Providing parents with written summaries of consultations highlighting key decisions about their child's treatment.
 - (b) Offering parents the opportunity to speak to clinicians without their child being present.
 - (c) Ensuring that sufficient time is available for parents to ask questions.
 - (d) Advising parents about the systems used to ensure continuity of care.
 - (e) Delivering test results in a sensitive, non-judgemental way.

Next steps

The findings have highlighted the need for further research to develop better support for parents of children with type 1 diabetes. Following on from the study, DR has applied for and been awarded a competitive fellowship by the Scottish Government – Chief Scientist Office (CSO). Work on this fellowship is currently underway and will draw on the findings presented above to develop an intervention to support the parents of children with type 1 diabetes. ■

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“Health professionals could help parents make more effective use of consultations and improve their child's clinical outcomes by: providing them with written summaries of consultations highlighting key decisions about their child's treatment; offering parents the opportunity to speak to clinicians without their child being present; ensuring that sufficient time is available for parents to ask questions; advising parents about the systems used to ensure continuity of care; and delivering test results in a sensitive, non-judgemental way.”