Management of children with type 1 diabetes during illness: a national survey

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ABSTRACT

Aim Adequate sick-day management at home can reduce the risk of progression to diabetic ketoacidosis and admission to hospital. The aim of this project was to review the management of diabetes during illness.

Method The Association of Children's Diabetes Clinicians (ACDC) carried out a questionnaire survey of all paediatric diabetes units. In addition, parents of children with type 1 diabetes completed an online questionnaire.

Results The survey of 127 units had a 73% response rate. Sick-day management guidelines were in place in 93%. All guidelines advised giving extra insulin during illness. In 67%, the extra dose was based on a fraction of total daily dose. 22% used units per kg body weight (U/kg). 21% used locally derived formulae to calculate extra dose of insulin. 3% of units advised only blood ketone monitoring. Although all units had an out-of-hours access policy for the families, 45% received advice from the general paediatric registrar. Only in 15%, the advice was directly from a member of the paediatric diabetes team. 680 parents completed the questionnaire. 86% reported receiving training on managing sick days. The majority (52.2%) receiving an informal session at diagnosis. 40% did not know what to do in the presence of raised blood glucose and high blood ketones.

Conclusions There was a wide variation in the practice of monitoring and advice given during illness. Both surveys highlight need for national guidance as well and to improve quality of sick-day rule education programmes for parents of children with type 1 diabetes.

INTRODUCTION

The effect of illness on children with diabetes generally raises the blood glucose levels. The increased secretion of counter-regulatory hormones due to the stress of illness produces a state of relative insulin resistance. It also leads to gluconeogenesis and impaired peripheral uptake of glucose causing hyperglycaemia and hyperosmolality. Insulin deficiency causes lipolysis, hepatic fatty acid oxidation and formation of ketone bodies.[1] Cytokine release in response to infection can also lead to insulin resistance.[2] If adequate insulin is not given and hydration is not maintained, this can result in diabetic ketoacidosis (DKA). Illnesses like gastroenteritis can reduce blood glucose levels with possibility of hypoglycaemia. Ketone bodies may still be produced in significant quantities.[3]

The International Society for Pediatric and Adolescent Diabetes (ISPAD)[3] clinical practice consensus guideline 2014 recommends adequate hydration, monitoring urine or blood ketones during illness and the administration of 5%–20% of total daily insulin or 0.05–1.0 units per kilogram body weight (U/kg) depending on level of ketones present. Children on insulin pump may increase their basal rate by an additional 50%–100% of the total basal rate. Appropriate management and monitoring during illness will prevent the need for hospital admissions and the risk of DKA.[4] National Institute for Health and Care Excellence (NICE) guidelines also recommend that children and young people with diabetes should be offered clear guidance for the management of diabetes during periods of illness.[5] It has been shown that adequate management of sickness at home with self-monitoring of blood sugars, ketones and administration of supplemental insulin and fluids leads to reduced hospitalisations and potential cost savings.[6]

The UK currently does not have a consensus guideline for sick-day management advice to children and young people with type 1 diabetes mellitus. This survey aimed at establishing the current practice in the UK.

METHODS

All 127 paediatric diabetes units (in England and Wales) were asked to complete a postal questionnaire which asked about their local sick-day management rules, out-of-hours diabetes support for the families and information about the local diabetes service. Reminders were sent using the regional networks and data were collected between April 2014 and March 2015.

Between October 2014 and February 2015, parents of children with type 1 diabetes living in UK were invited to complete an online questionnaire which was posted on web-based forums popular with the parents of children with diabetes. The questionnaire was validated for consistency by a panel of parents who were national committee members of 'Families with Diabetes National Network' (a network that represents families of children with diabetes in the UK; regional representatives make up the national committee). The questionnaire was set up to allow for only one response per internet protocol address.

RESULTS

A total of 93/127 (73%) of the units responded to the survey. There were 14 tertiary centres and 79 district general hospitals.

Service details

Median number of children per unit were 161 (range 73–450). There was a wide variation in healthcare staffing and patients per unit (table 1).

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Table 1 Staffing per service

Healthcare professional (HCP)	Number of HCP per unit Median (range)	Patients per unit Median (range)
Diabetes nurse specialist	2.6 (0.9–6.1)	65 (37.5–136.7)
Dietician	1 (0.1–4)	191.6 (64–1100)
Psychologist	0.4 (0.025–1)	414 (0–2500)
Diabetes clinicians	1.2 (0.25–3)	125 (55–618)

Insulin regimens

There was variability in the insulin regimens nationally. The most common insulin regimen was multiple daily injections. Median number of patients using this regimen were 67.3% (range 34.4%–95.6%). Median number of insulin pump users was 25% (range 0%–64%). 2.4% of patients were on twice or thrice daily insulin regimen (range 0%–59%).

Sick-day management guidelines

A total of 86/93 (92%) of the respondents had a sick-day management guideline in place. A total of 68/93 (73%) had a separate protocol for the patients on insulin pumps. A total of 70/93 (75%) had the guidelines on the hospital intranet, so it was easily accessible for the hospital staff.

Only 70 (75%) of the respondents provided a written copy of the sick-day guideline to all the patients. In six units, written information was only given to patients on insulin pumps.

Sick-day management

During sick-day management, increased amount of insulin was calculated as a percentage of total daily dose by 63/93 (67%) of the units, 22% (21/93) used the U/kg rule and 15/93 (16%) used both. A total of 21% (20/93) units used some other locally derived rule to calculate the increased amount of insulin needed.

A total of 50/93 (53%) of respondents advised blood ketone monitoring; however, 34/93 (40%) were using both blood and urine testing and 3/93 (3.2%) used urine testing only. Most of the units which were using both blood and urine testing were training newly diagnosed and patients on pumps to use blood ketone testing only.

Out-of-hours advice for children and families

Advice to the families regarding management of illness outside of normal working hours was provided by a general paediatric registrar on call in 45% of units (42/93), by a paediatric diabetes specialist nurse (PDSN) in 6/93 (6.5%) and in 8/93 (8.5%) by a paediatric diabetes consultant on call. In 27% (23/86), advice was given by PDSN and diabetes consultant on a joint rota.

Parent and carers survey

Six hundred and eighty responses were recorded. The survey tested parental knowledge on four domains of sick-day self-management: glucose monitoring, ketone monitoring, fluid intake and supplemental insulin administration. It also sought information on their experience of self-management education programmes and telephone support.

Eighty-six per cent of the parents reported receiving training on managing sick days. The majority (52.2%) received this as an informal session at diagnosis. A total of 32.7% reported that they received an information leaflet only with no formal or informal teaching session. A total of 80% of parents received this training shortly after diagnosis with only 6.3% receiving regular updates. A total of 25% said that they received updates on occasions when their child was ill. When asked about out-of-hours support for the families, 52.1% had access to their diabetes team, while 14.6% had access to ward staff/paediatric registrar for advice. Other popular sources of information when dealing with illness included other parents (49.2%), Facebook (63.3%) and Google (31.5%). Forty per cent either did not know what to do in the presence of raised blood glucose and high blood ketones or would have taken no action to prevent DKA.

DISCUSSION

This survey was conducted to establish baseline current practice in the sick-day management of diabetes in children with type 1 diabetes. It was found that even though all the units had access to a PDSN, dietician and a psychologist, there remains wide variation in patient-to-care-provider ratio.

Worryingly, 8% of units in our study did not have a sick-day management guideline in place for either health professionals or the families. In the UK, there is no national consensus on managing illness in children with type 1 diabetes. Various international recommendations (ISPAD,[3] American Diabetes Association,[7] Australasian Paediatric Endocrine Group[8]) advise increasing insulin doses during illness either based on total daily doses or U/kg. This is the practice in majority of the units although a small number of units used a variety of locally derived rules. The current recommendations by the various societies are based on consensus or good practice. There are no clinical trials comparing one rule with the other.

Studies have confirmed that blood ketone testing is superior to urine for preventing as well as managing DKA.[9] Patients are also less likely to test their urine for ketones than blood. A study comparing blood and urine ketone testing showed that blood ketone testing can actually lead to reduced hospital admissions.[10] In spite of such evidence, a significant number of units (40%) were still advising urine ketone testing. As patients on pumps are more at risk of developing DKA quickly due to pump malfunctions, blood ketone testing leads to earlier detection of ketosis allowing for preventative action to be taken. In our survey, 66% (62/93) of the units advised their patients on pumps to use ketone testing.

There is evidence to suggest that access to 24 h advice on diabetes care can reduce admissions and length of stay with DKA in children and young people with established diabetes. This can be effective when delivered by PDSNs as well as non-diabetes team staff provided there is training for staff responding to emergency calls and agreed guidelines in place. An Italian study showed that introduction of a toll-free 24 h hotline managed by staff with some experience in diabetes helped to avoid hospital admissions during sickness.[11] Our survey has highlighted that there is a wide variation in the patient-to-healthcare-professional ratio nationally. In spite of that, in the majority of units, out-of-hours advice was provided by the general medical on-call team with access to a diabetes specialist. There was no relation between the patient load and access to members of diabetes team by the patients.

Diabetes self-management is the process of providing children and young people with diabetes education, knowledge and skills needed to successfully manage their diabetes.[12] Children with better self-management have reduced rates of DKA.[13] Periodical reinforcement of sick-day rules is important mainly during flu season or start of school year to keep families up to date and it might reduce the incidence of DKA.[6] Only a minority of

parents in our study reported having formal structured education with annual updates. According to National Paediatric Diabetes Audit report for 2011–2012, 30% of hospital admission in children with established type 1 diabetes were due to DKA.[14] It is therefore not surprising that a significant number (40%) either did not know what to do in the presence of raised blood glucose and high blood ketones or would have taken no action to prevent DKA.

We had 680 responses to our parental survey. As this was an online survey, it included parents from the diabetes national network and Facebook site. We understand that this is a relatively small number and may not fully represent the social and ethnic diversity of the families nationally. However, a significant number of parents reported getting advice from internet sources or other friends. This clearly poses some dangers as it is not possible to always be certain of the accuracy of the information and erroneous information can lead to delay in seeking treatment. Parents and children need to be provided with appropriate training and support in the management of sick days as better self-management skills lead to reduced rate of DKA.[13]

CONCLUSION

This survey has highlighted significant variations in the management of illness (sick days) in children and young people with type 1 diabetes. Both healthcare professionals and parents' survey results highlight the need for evidence-based national guidance as well as the need to improve quality of sick-day guidance education for parents and carers of children and young people with type 1 diabetes. Based on the results on this survey, Association of Children's Diabetes Clinicians (ACDC) committee has developed an evidence-based national guideline for management of illness in children with type 1 diabetes.[15]

Main messages

- There is significant variation nationally in the management of illness in children with type 1 diabetes.
- There is lack of formal structured education and annual updates for parents and children with type 1 diabetes in sick-day management.
- This study highlights the need for development of an evidence-based national consensus guideline for management of sick days in children with diabetes.

Current research questions

- Methods for calculating increased amount of insulin—which one is better?
- Increased amount of fluids during periods of illness—which is the best fluid and how much?
- What is the best method to provide structural education for parents and children with type 1 diabetes—one-to-one sessions or small groups?

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Competing interests None declared.

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