INDEPENDENT DIABETES TRUST Newsletter Parents Bulletin



June 2014 Newsletter

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The relationship between maternal fear of hypoglycaemia and adherence in children with Type 1 diabetes

Results

Blood glucose levels were higher in the children of mothers with high fears of hypoglycaemia and this was regardless of the length of time their children had diabetes or the age of diagnosis. This suggests that mothers who worry most about hypos compensate by running their child's blood sugars above the recommended level.

This study looked at the relationship between the mothers' beliefs about diabetes, concerns about hypoglycaemia and blood glucose control, and adherence to the recommended blood glucose levels in young children with Type 1 diabetes.

71 mothers with children under 13 were involved in the study. They reported their hypoglycaemic fears and illness perceptions at the outset of the study. They also reported the daily blood sugar levels of their children for a week and HbA1cs were recorded at the beginning of the study and 3 months later.

Comment

If we are honest, how many of us do just this? I certainly know that after a severe night hypo, I raised my daughter's blood sugars for 2 or 3 weeks to avoid another one and I also didn't sleep well for quite a long time. In fact, it was a bit like having a new baby – always one ear listening.

I have had many years to think about this and have come to the conclusion that it is a fairly normal reaction to a severe hypo, even though I was, and still am, aware of the dangers of running blood sugars higher than recommended.

I was 'lucky' in that during the day even from a young age, my daughter knew when she was hypo. Well, not strictly true but she recognised when she 'felt funny' and could tell me or her teacher.

One to one classroom assistants and/or hypo dogs were not an option when my daughter was young and of course, we managed. Some parents have arranged classroom assistants for their children at school, and sometimes a hypo dog, so what has changed over the years?

- Are young children with Type 1 diabetes in more danger now than they were 20 or 30 years ago?
- Are the targets set too low, so that children are having more hypos?
- Do more children have hypo unawareness now than they did? [This expression didn't arrive on the scene until the late 1980s.]

A charity supporting and listening to people who live with diabetes

Charity Number 1058284 Registered Number 3148360

- Are parents in greater fear of hypos now than they were? If their children don't have hypo warnings, then it is not surprising they need a one to one classroom assistant.
- What is different about treatment today?

These are all questions that need answering so that children with diabetes can go to school and not be 'different' from other children in the class. Thirty or forty years ago, as parents, we were fighting battles for our children not to be treated differently from other children at school so that they did not feel different from their friends or isolated. It seems that we have come a full circle as teaching assistants and hypo dogs are bound to make children with Type 1 diabetes feel different from their friends, so what has changed? For all the children with Type 1 diabetes, we need to know.

Parents in London are the least likely to report drug side effects in their children

Research conducted on behalf of the Medicines and Healthcare products Regulatory Agency [MHRA] has shown that parents in London are the least likely in the UK to tell their GP, pharmacist or healthcare professional about adverse drug reactions experienced by their children.

- 69% of parents in London said they would report a side effect to a doctor compared to 88% in Wales.
- 39% would ask their pharmacist compared to 59% of parents in Wales.

However, London parents were the most aware that they could report side effects using the MHRA's Yellow Card Scheme with 14% of parents knowing about the Scheme compared to an average of 9% across the rest of the UK.

The research was carried out as part of a campaign to increase reporting side effects of children's medicines by parents and carers.

What is the Yellow Card Scheme?

The Scheme collects and reports side effects to medicines and vaccines and is used to monitor the safety of medicines, vaccines and complementary medicines. It acts as an early warning system for identifying previously unrecognised adverse drug reactions, but also provides valuable information on recognised side effects. It is also used to detect medication errors and problems when medicines are used off label (medicines that have not received marketing An article first published online in Pediatric Diabetes 3 April 2014, investigated the effects of metformin on diabetes control and insulin sensitivity in adolescents with Type 1 diabetes.

Metformin is the most common drug used to treat Type 2 diabetes. It does not increase insulin production and therefore does not cause hypoglycaemia, but it increases the body's ability to use the insulin more effectively so increases insulin sensitivity.

This study was designed to explore whether adding metformin to the treatment will improve blood glucose control in adolescents with Type 1 diabetes between the ages of 13 and 20 years. There were 74

approval) and misused by patients, such as intentional or accidental overdose. This allows the MHRA to identify and refine understanding of potential safety issues that may affect the treatment of patients. It is also used to update prescribing advice for health professionals.

The side effects only have to be suspected, not proved and can be reported by the general population and by healthcare professionals. It is estimated that only 10 to 15% of serious side effects are reported by the whole population and reporting for children is nearly half that number.

The MHRA is particularly keen to receive reports about suspected side effects of drugs in children as children can react differently to medicines compared to adults as their body may handle the medicine differently.

Yellow card forms can be obtained from GP surgeries, by emailing <u>yellowcard@mhra.gsi.gov.uk</u> or by downloading them from the Yellow Card website:

www.yellowcard.mhra.gov.uk/the-yellow-card-scheme/

[Press release by MHRA, 05.03.14]

Effects of low dose metformin in adolescents with Type I diabetes mellitus

participants who were divided into two groups – one group was given the addition of metformin and the other group stayed on their usual insulin only treatment.

HbA1cs, insulin dose, waist circumference, BMI and blood pressure were measured at the start of the study and at 3 and 6 months. Fasting lipids were also measured at the beginning and after 6 months.

Results

- In the metformin group, BMI and waist circumference significantly decreased at 3 and 6 months compared to the insulin-only group, even in those of normal weight.
- In the insulin-only group, total insulin dose and systolic blood pressure increased significantly at 6 months.
- There was no significant change in HbA1cs between the two groups at any point in the study.

Conclusions

The researchers recommend that further studies are carried out to confirm these results. They say that the results from this study suggest that low dose metformin improves BMI as well as insulin sensitivity in adolescents with Type 1 diabetes. The decrease in waist circumference also suggests that metformin alters fat distribution.

holiday **TIPS**

Holidays are approaching and whether staying in this country or going abroad, for families with diabetes, this means more planning and a bit more care when you are away. If you would like one of our packs of Holiday Tips, just call IDDT on 01604 622837, email enquiries@iddtinternational.org or visit our website homepage www.iddtinternational.org.



Schools will have a legal duty to look after children with diabetes

The Children and Families Bill is to include a legal duty for schools to support children with long-term conditions, including Type 1 diabetes. This will apply to all schools, including free schools and academies and should mean that schools have a clear responsibility to look after children with medical conditions from September 2014. Schools will need to work with parents, local authorities and health services to develop a policy and individual health care plans. Ofsted will be monitoring the new rules and will issue inspection guidance to take into account new duty.

Responsibility for the right to access to insulin pumps

NHS England is responsible for making sure that people with Type 1 diabetes get the right to access to insulin pumps, according to a statement by Health Minister, Jane Ellison, on March 28th 2014. She stated that it is down the NHS England to ensure that local NHS organisations make pumps available to people with Type 1 diabetes who meet the NICE criteria and that insulin pumps should be available to:

• Children with Type 1 who are under 12 if having multiple daily injections is impractical or inappropriate.

• Anyone with Type 1 diabetes over the age of 12, provided that multi-daily insulin injections have not worked. This means people who do not meet recommended blood glucose levels despite multiple daily injections and a high level of care or if they cannot do this without disabling hypos.

Healthcare app to help children with Type 1 diabetes

An app called Monster Manor is available in the UK aimed at helping children with Type 1 diabetes to manage their condition. Children often do not want to test regularly and this can be a source of argument in a family, so the app has been developed to encourage children to test and record their blood glucose levels more regularly.

Monster Manorfor iPod, iPhone, iPad and Android is free to download from the Apple Store or Google Play.

Flu vaccinations to expand in September

GP practices will be asked to give flu jabs to all fouryear-olds next winter as part of the national vaccination programme after pilot studies using the Flenz vaccine in this age group have been carried out in parts of England. A new round of pilot studies of the flu vaccine will be rolled out from September in 11 to 13 year olds.

IDDT News

Changes to the Parents Bulletin

As readers will have realised, like many charities IDDT is suffering financially in the present economic climate so we have had to look at ways to save money. Producing the separate Parents Bulletin is costly and many of our parent members also receive the Newsletter, so we have had to take the decision to increase the size of the Newsletter to include a section for parents of children and young people with diabetes. Around half of our members have Type 2 diabetes, so our Newsletter for them, Type 2 & You, will continue to be published.

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America approves continuous glucose monitoring system for children

In February this year, the US Food and Drugs Administration (FDA) expanded approval to the Dexcom G4 Platinum Continuous Monitoring System to include children with diabetes aged 2 to 17 years. The device has previously been approved for use in adults only.

The externally-worn device continuously displays an estimate of blood glucose levels and the direction and rate of any changes in levels. It is intended to be worn for up to seven days and is meant to be used in addition to standard home glucose monitoring devices, not as a replacement.

Clinical studies involved 176 children and young people between the ages of 2 and 17 years. The FDA warned that the device was not as accurate in children as its performance in adults but said that the device is 'still effective for tracking and trending to determine patterns in glucose levels.'

Faults found in FreeStyle Mini and FreeStyle meters

Faults have been found in some glucose monitors, which could show incorrect low blood sugar results. Abbott Diabetes Care has recalled their FreeStyle Mini Blood Glucose Meter and FreeStyle Blood Glucose Meter because they may give incorrect low blood glucose results when they are used with FreeStyle Lite and FreeStyle blood glucose test strips.

Around 11,000 people in the UK are using these models although they have not been sold in the UK since 2007. Users have been urged to contact the retailer to receive a free updated meter. Or they can telephone Abbott Diabetes Care on 0500 467 466 who will provide a new meter.

While waiting for a replacement meter, the Medicines and Healthcare products Regulatory Agency (MHRA) has advised people to continue to monitor their blood glucose levels using their existing models but to take extra care to notice of any signs of high blood glucose levels. (19 March, 2014)

Have you seen Journal Watch on our website?

Every month we have a new edition of Journal Watch, prepared for IDDT by Jim Young, on the homepage of our website www. iddtinternational.org. Journal Watch highlights recent studies into various aspects of diabetes. In March there were a couple of research items that may be of particular interest to parents of children with Type 1 diabetes, so here they are.

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

David Rankin et al. Pediatric Diabetes. Doi: 10.1111/pedi.12124

This study looked at the reasons for delays in seeking treatment and parents' emotional reactions to diagnosis. The methodology involved in-depth interviews with 54 parents of children (aged 12 yrs or under) with type 1 diabetes (T1D). The 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 health care 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. These parents often only sought medical help when symptoms became extreme. The authors posit that campaigns to raise awareness should ensure that parents are made aware of symptoms and that T1D can develop during childhood. They also suggest that health care professionals could discuss with parents the events preceding their child's diagnosis to better determine their emotional support needs.

Insulin pump use in young children in the T1D Exchange clinic registry is associated with lower HbA1c levels than injection therapy

Scott M Blackman et al. Pediatric Diabetes. Doi: 10.1111/pedi.12121

In this study insulin delivery via injection and continuous subcutaneous insulin infusion (CSII) via insulin pump were compared in young children under 6 years with type 1 diabetes (T1D). It was found that the use of CSII correlated with longer T1D duration and higher parental education. Wide variation in pump use was observed which suggests that prescriber preference is a substantial determinant of CSII use. It was also found that HbA1c was lower in pump vs. injection users, whilst the frequency of a severe hypoglycemia (SH) event did not differ in pump vs. injection users. However, the frequency of parent-reported diabetic ketoacidosis (DKA) events in the prior year was greater in pump users than injection users. No differences between pump and injection users were observed for clinic-reported DKA events. The authors assert that their data support the use of insulin pumps in this youngest age group, and suggest that metabolic control may be improved without increasing the frequency of severe hypoglycaemia, but care should be taken as to the possibly increased risk of DKA.

http://onlinelibrary.wiley.com/doi/10.1111/pedi.12124/abstract

http://onlinelibrary.wiley.com/doi/10.1111/pedi.12121/abstract

Research

Afternoon exercise and the effects on hypoglycaemia in adolescents

Research has shown that in adolescents with Type 1 diabetes a 30 minute increase in moderate to vigorous exercise in the afternoon or evening results in an increased risk of overnight or next day hypoglycaemia. The adolescents were between the ages of 14 and 20 years old. The importance of this study is that this is often the time when young people have extra physical activity at school or during their hobbies in the evening.

The research also showed that the adolescents who were more physically fit have a greater increased risk of hypoglycaemia the next day compared to those who were less fit. This study emphasises the need to educate young people about the risks of hypos if they are taking activity in the afternoon or evening. (Diabetes Care, March 2014)

Identifying adolescents with Type 1 at risk of kidney and heart disease

An international study has found that a simple urine test can be used to identify young people with Type 1 diabetes who are at risk of heart and kidney disease. The study involved 3,353 adolescents with Type 1 diabetes between the ages of 10 and 16. The researchers found that participants whose albumin levels were in the top 30% but still within the normal range, showed more evidence of kidney and cardiovascular problems than those with lower levels.

Up to 40% of young people with Type 1 diabetes are at risk of kidney disease which also increases the risk of heart disease. Raised albumin levels are used to identify adults with diabetes at higher risk of these complications but this is the first time that this measure has been used to show a similar risk in adolescents. Now that early screening can identify at risk young people, the next step in the research is to find out if drugs such as statins and blood pressure tablets could help to reduce the risk of kidney and heart disease in adolescents. [Diabetes Care, November 2013]

Seasonal variations in HbA1cs in children

We published this article some time ago but it is well worth reading again...



Doctors

Doctors are calling for better diabetes awareness as almost 1 in 5 children with diabetes develop diabetic ketoacidosis (DKA), a potentially dangerous complication due to a lack of insulin in the body, before they are officially diagnosed with the condition.

In addition, according to a report from the National Paediatric Diabetes Audit (NPDA) published by the Royal College of Paediatrics and Child Health, rates of DKA in those already diagnosed with diabetes remain high and are highest in females aged between 10 and 19 in England and Wales. If left untreated, DKA can cause mental confusion, rapid heartbeat

and breathing, sickness and unconsciousness and can be life threatening if not diagnosed and treated urgently.

The Audit identified 6,210 hospital admissions out of 25,199 children and young people under the age of 25 with diabetes for 2011-12 who are cared for in 177 paediatric centres across England and Wales. The Audit also found:

- approximately half of all hospital admissions in children with diabetes are related to acute complications including DKA and hypoglycaemia.
- The number of admissions for DKA remain high but have improved since 2010-11 with females tending to have higher rates of DKA admissions than males.

Research was carried out to find out if HbA1c levels vary with weather conditions. HbA1c levels were measured over more than 3 years in children and young people under the age of 18 with Type 1 diabetes for more than a year. The results were correlated with weather conditions – ambient temperature, hours of sunshine and solar irradiance. A total of 3,935 HbA1c measurements were taken in 589 children aged 7 and over and in 88 children under 7 years old.

Results

- The lowest HbA1cs were in late summer and the highest were in the winter months with the differences being consistently more than 0.44%.
- There was a pattern over 12 months which mirrored changes in the ambient temperature.
- There was a relationship between HbA1cs, ambient temperature, hours of sunshine and solar irradiance present in the children 7 and over but not in those under 7 years old.

The importance of these findings

- The researchers suggest that these seasonal variations in HbA1c levels in schoolchildren with Type 1 diabetes are significant and should be considered in patient education and diabetes management.
- Potentially they could affect the results of clinical trials where HbA1cs levels are used as a primary outcome. For example, if comparing two treatments where the primary outcome is a comparison of HbA1c results, then if these vary with seasons, the study would have to take this into account for the results to be accurate and reliable.
- If HbA1cs are used for diagnosis of Type 1 diabetes as is starting to happen, then his seasonal variation could need to be taken into account.

[Diabetologia DOI: 10.1007/s00125-010-2013-4]

call for better awareness of diabetes in children

- Nearly 1 in 10 admissions to hospital of children and young people with diabetes is as a result of hypoglycaemia.
- A surprise finding was that over half of all admissions to hospital in children and young people with diabetes are coded as 'without complications'.

In view of this report, doctors are calling for the public, health professionals and parents to be more aware of the classic symptoms of Type 1 diabetes – thirst, needing the toilet frequently, being more tired than usual and loss of weight. Many children only have one or two of these symptoms but it is important that parents are aware of all four symptoms to avoid children not being diagnosed until they have DKA.

The report can be found at:

http://www.hqip.org.uk/assets/NCAPOP-Library/ NCAPOP-2013-14/NPDA-2011-12-complications-report-v5-FINALfor-publication-Feb21-2014.pdf

Action needed on Vitamin D

There has been much talk about vitamin D or more accurately, the deficiency of vitamin D. This has been the subject of a debate amongst experts. The key points were:

- an estimated 40% of young children are deficient in vitamin D and in recent years there has been a four-fold increase in the number of cases of the bone disease, rickets.
- Sunshine is a source of vitamin D and safe sun messages have reduced people's exposure to the sun which has added to the cause of deficiency levels.
- There are particular risks in some ethnic communities: dark-skinned people need more sunshine to make vitamin D, and some groups cover up more and so get less sunshine.

• There are difficulties getting the right messages out to mothers of infants: baby formula is fortified with vitamin D by law, but breastfed babies need supplements.

The general consensus was that the current messages to the general public were too complicated, and that a clearer and multi-pronged approach needed to be taken.

Note: Recent research suggests that vitamin D deficiency precedes the onset of Type 1 diabetes and this may be a consequence of an immune response. Therefore the researchers suggest in the case of pre-diabetic children, vitamin D deficiency should be considered and it may be that supplements of vitamin D should be considered at an early stage in Type 1 diabetes. [Diabetologia March 2014]

IDDT's Conference

2014 is our 20th Anniversary, so we are holding a conference that hopefully is a little bit special to celebrate the formation of IDDT and some of our achievements. You will see from the conference booking form, accompanying this Parents Bulletin that it should be an interesting day and we hope that many of you will be able to attend. A date for your diary - October 18th 2014!

As the conference is celebrating our 20th anniversary, we have decided to hold our Annual General Meeting on a separate day. This meeting will be held at the Kettering Park Hotel and all members are welcome to attend. This meeting will start at 2.00pm on Wednesday, October 29th 2014.

INDEPENDENT DIABETES TRUST



Diabetes

Food, Meds and More

The recipe book with a difference

For the first time, IDDT has published a book entitled '*Diabetes – Food, Meds and More*'. It is a recipe book with a difference for people with Type 1 and Type 2 diabetes and for those at risk of diabetes.

The book was co-written by Martin Hirst and Mabel Blades, the authors of '*Diabetes* – *Everyday Eating*' - IDDT's most popular booklet, nearly 160,000 copies of which have been supplied in less than two years.

'Diabetes – Food, Meds and More' is not a typical recipe book, as it aims to cover real life, the day to day situations that happen. It not only includes everyday meals but also what to eat if you are ill, when you are taking exercise, if blood glucose levels are low, if you are travelling or if you are having a party. It also has sections for people with diabetes and coeliac disease, a lifestyle essential, and for vegetarians and vegans with diabetes, lifestyle choices.



The book aims to cover:

Management – the different types of diabetes and information on lifestyle issues.

Medication – the ways Type 1 and Type 2 diabetes are treated, including information on different types of meals and how these link with insulin, medication and physical activity.

Meals – recipes and ideas for meals and snacks, including those for special occasions.

Thanks go to the people living with diabetes who have asked our charity for more information about food, drink and meals that they can eat safely. They and their needs are the inspiration for this book.

'Diabetes – Food, Meds and More' costs £8.99 but is available to IDDT members for £7.99.

An order form is enclosed with this Newsletter so to order your copy, complete the form and return to

IDDT, PO Box 294, Northampton, NN1 4XS.

Alternatively you can order by telephone on 01604 622837 or online at www.iddt.org/iddt-shop

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