Diabetes in children and young people: Optimising management throughout the care pathway

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The number of children and young people (CYP) with diabetes is growing, particularly in the under fives. Optimising diabetes management as early as possible is essential and this requires the highest standard of inpatient care. The implementation of the Paediatric diabetes best practice tariff in England means that in-depth clinical assessment of both psychosocial and physical health by the multidisciplinary team will now be possible. This in turn, will enable paediatric diabetes nurse specialists to ensure earlier implementation of evidence-based practice from diagnosis. This article will discuss aspects of diabetes management, including key practical skills and two case studies of children with type 1 diabetes. Both case studies reflect on the challenges faced within the ward environment, the role of inpatient staff, along with insight into the perspective of CYP and their families.

Education for inpatient staff

The education of inpatient staff is essential to ensure consistency of information at diagnosis. The specialist team should enable staff to develop these skills by providing invitations to attend workshops and study days, as well as asking staff to observe clinics and pump starts and to be involved in peer review (NHS Diabetes [now part of NHS Improving Quality], 2012a). Inpatient staff should be invited to attend team meetings at least annually. This can provide opportunities to make team goals explicit and ensure consistent high-quality care throughout the care pathway.

According to the audit by Edge et al (2013), out of all the audit standards, education for inpatient staff was least likely to be achieved, despite featuring in 89% of paediatric diabetes specialist nurse (PDSN) job descriptions. The reasons for this are likely to be multifaceted but inspirational leadership, coupled with the concentration of staff expertise on one ward (as is the case with conditions such cystic fibrosis and childhood cancers) has been suggested as key to a successful ward environment (Edge et al, 2013). Following on from the launch of the national core curriculum (SWEET and NHS Diabetes, 2012), a “basic awareness” e-learning module is currently being piloted. This has the potential to add more value, providing accessible and affordable learning...
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Insulin safety is a national problem (Lamont et al, 2010) and although not currently mandatory, the “Safer use of insulin” e-learning module developed by NHS Diabetes has demonstrated a significant reduction in errors since its launch (James, 2013). Half of all centres in the children’s inpatient audit recorded insulin-related prescription errors during admissions (Edge et al, 2013). This emphasises that insulin safety training must be a key recommendation.

In Leeds, reflection on the level of support provided by the children and young people (CYP) diabetes team to inpatient staff locally led to the development of diabetes-specific documentation and prescription charts relating to diabetic ketoacidosis (DKA), insulin pump therapy and multiple daily insulin. These documents cover multiple basal changes, correction doses, carbohydrate ratios and methods of calculation to ensure robust systems that minimise risk. They are available through the CYP diabetes module at the University of York.

In order to monitor the inpatient experience, the team in Leeds have devised a short questionnaire, which was based on the “Friends and family test” (NHS England, 2012) but adapted for CYP with diabetes. This one-minute questionnaire (Box 1) is used to ensure families have a voice and local services can promptly respond to any concerns and improve standards of inpatient care.

**Structured education for CYP and families**

The Paediatric diabetes best practice tariff (Randell, 2012) states:

“Each provider unit can provide evidence that each patient has received a structured education programme, tailored to the child or young person’s and family’s needs, both at the time of initial diagnosis and on-going updates”

A structured age-differentiated curriculum, which meets Department of Health (DH) and Diabetes UK criteria (2005), has been developed locally in Leeds to support comprehensive and consistent education from diagnosis by the MDT and inpatient staff. Development of this curriculum may also reduce the number of missed opportunities for demonstrating and supporting practical diabetes skills.

According to Peyrot et al (2005), teams who shared the same goals as children and young people and their parents were shown to have the most significant impact on HbA1c and therefore were better able to reduce impact of complications.

**Box 1. Children’s diabetes inpatient experience: One-minute questionnaire**

Please answer the three questions using the scale (1 being poor, 10 being excellent) and a brief comment (both negative and positive) below; it only takes a minute!

1. How well did ward staff introduce themselves and explain clearly what would be happening?
   1 2 3 4 5 6 7 8 9 10 (please circle)
   What are you most likely to tell your friends and family about this?

2. How well did ward staff explain and demonstrate key areas, such as blood glucose monitoring, insulin injection technique and rotation, carbohydrate recognition and counting, hypoglycaemia signs and symptoms and treatment?
   1 2 3 4 5 6 7 8 9 10 (please circle)
   What are you most likely to tell your friends and family about this?

3. Overall, do you feel you were listened to and given the right amount of clear information before discharge home?
   1 2 3 4 5 6 7 8 9 10 (please circle)
   What are you most likely to tell your friends and family about this?
and is supported by research (Lange et al, 2007; Sassman et al, 2012) but, unfortunately, this is often seen as an “optional extra” in the UK (Juvenile Diabetes Research Foundation, 2013).

**New diagnosis of diabetes**

The diagnosis of diabetes is a significant and life-changing event and families have been known to refer to the loss of their “healthy child”. This psychosocial transition requires people to learn new ways of coping, understanding and behaviours. Hopson et al (1992) identified the “Seven transition stages model” (Box 2), which discusses the range of emotions and feelings experienced during this time. Case study 1 describes some of the challenges parents or carers face when their child is newly diagnosed and gives examples of how these problems are overcome.

**Role of psychology from diagnosis**

The importance of identifying psychosocial risk factors from the outset in CYP with diabetes is increasingly being recognised (Graue et al, 2004; Silverstein et al, 2005) and may help to provide tailored support that can protect against parental burnout (Haugstvedt et al, 2011; Lindström et al, 2011). Suggestions include identification of the most pressing needs in a family and finding the solution where possible. Furthermore, simply allowing expression of negative thoughts and feelings can help people to work through these problems.

Fear of hypoglycaemia and not recognising an episode are particular worries for the parents of very young children. Barnard et al (2012) recommend greater attention be paid to questions that elicit increased understanding of thoughts, feelings and behaviours, and “fear of hypoglycaemia” scales such as those devised by Polonsky et al (2005) are encouraged in order to support this process and tailor treatment.

Structured behavioural group training for parents may also

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**Box 2. Seven transition stages model (Hopson et al, 1992).**

- **Shock**: Awareness of emotions appears blocked.
- **Denial**: Importance of the change is minimised.
- **Self doubt and depression**: Experience of uncertainty and doubts related to how to control the new situation.
- **Acceptance of the new reality**: Acceptance of the new reality starts with detachment from the old patterns.
- **Analysis of the possibilities for resolution**: Individuals start to take a more active role through trying new coping strategies.
- **Looking for meaning**: The need for understanding how the individual’s future will be affected is developed.
- **Integration**: The new experience is fully incorporated and integrated in the individual’s life.
have a role and recent research from Sassmann et al (2012) has demonstrated this group training is effective in reducing parental stress and improving parental skills.

Therefore, encouraging CYP and their families to express thoughts and feelings must be a part of every contact and recognised as being as important as medication.

**Injection technique and rotation**

As with any clinical intervention, getting injection technique right from day one is essential. For the person with diabetes, learning the technique at such a vulnerable time has a high impact and is long lasting, and the skill can be used several times each day.

Recent research by LoPresti et al (2012) has identified that CYP have minimal subcutaneous fat and consequently there is a strong case for the use of 4 mm pen needles (with a lifted skin fold in those under 6 years) in order to avoid intramuscular...
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3. Transition from child to adult services should not simply be a transfer of care but requires a focus on adolescent healthcare needs. In order to support this process, each unit must have a clear policy for transition to adult services.

Injections, which can result in unpredictable glucose levels. Lo Presti et al (2012) have identified the buttocks as the site with most subcutaneous fat and Hicks et al (2011) highlight that the buttocks have a long, slow absorption rate making this the ideal site for the first taught injection. Actively recommending the use of this site from the outset, rather than leaving this to parents to attempt to change at home, will further support best practice from diagnosis. However, it is important to note that the injection site used for the first injection will depend on the individual child and individual circumstances. For example, some children might prefer to be able to observe what is happening, or inject themselves. Informed decision-making based on evidence-based information and individual assessment is key.

Hanas (2004) notes that the use of a local anaesthetic cream can be helpful for insulin pump changes and this idea has been adapted in our team and is used in children under 5 years, if there is a fear of needles. Other methods, such as the use of a ward play specialist in young children or cognitive behavioural approaches such as relaxation and guided imagery in older children, can add further value to this intervention. This is also helpful for finger prick tests and cannula insertion.

From diagnosis, families need to be advised of the importance of rotation between injection sites as well as between different sites of the body (Chowdhury and Escudier, 2003) as this decreases the risk of lipohypertrophy. In young children, easy-to-follow rotation techniques and devices, such as visualising a clock face or a key pad for older children, can encourage full use of one site before moving to the next.

**Numeracy skills**

In a study of diabetes healthcare professionals, Kerr and Varshneya (2012) highlighted that a significant number of people with diabetes face challenges with numeracy skills and this can impact on their ability to self-manage. Assessment of the numeracy skills of CYP and their families is essential from the outset so that they receive extra support if necessary. Using the individual’s preferred formula to work out the carbohydrate:insulin ratio and correction doses and then ensuring consistency with calculating at every contact is essential to avoid confusion.

Alternatively, bolus decision support tools can be set up by the healthcare professional and then reviewed at each contact. In CYP, such tools can also support consistency in decision making between parents, carers and children as well as facilitating early identification of glycaemic excursions and a prompt review of settings, avoiding blame and supporting interdependence (Schilling et al, 2002).

**DKA and insulin omission**

Results from the audit of children’s diabetes inpatient care (Edge et al, 2013) suggest that within one year, approximately 8.8% of children with diabetes are admitted to hospital with DKA.

In Leeds, building sufficient knowledge and skills for an efficient and effective 24 hour out-of-hours service on a designated ward has served to reduce feelings of vulnerability in our local service. The out-of-hours service includes agreed evidence-based pathways and an escalation policy that states when to contact the specialist team. Edge et al (2013) found when CYP with diabetes were admitted, only 26% of PDNS and 15% of consultants were contacted within 2 hours.

Insulin omission is a common reason for DKA in CYP with existing diabetes and, as there are usually important psychosocial reasons for this (Wolfsdorf et al, 2009), an in-depth MDT assessment during the admission is vital in uncovering the root cause. This should be followed up with a routine referral to the team psychologist.

**Adolescent health and transition**

As with other life stages, such as starting school, adolescence is a period of significant change and realignment. Transition from child to adult services should not simply be a transfer of care but requires a focus on adolescent healthcare needs. In order to support this process, the Paediatric diabetes best practice tariff requires that each unit in England must have a clear policy for transition to adult services (Randell, 2012).

Policy documents such as the Diabetes transition document (NHS Diabetes, 2012b) and Not just a phase (RCPCH, 2010) highlight that is it very important to create the right culture and to get young people’s full participation in services. Additional training in communicating with young
people has also been recommended in Quality criteria for young people friendly health services (DH, 2011). This is particularly important as health behaviours set down in adolescence are carried through to adulthood (Viner and Barker, 2005); therefore getting it right at this stage is pivotal to long-term health. In addition, the research carried out by Allen and Gregory (2009) helps in considering the range of models available for this transition, with in-depth reflection on their component parts.

Healthcare professionals who are involved in the transition from paediatric to adult services may be interested in the RCPCH Adolescent Health Programme (available at: www.rcpch.ac.uk/AHP). There is also a new learning module developed at the University of York, in collaboration with Leeds Teaching Hospitals Trust, which has just been launched in a response to the DH’s plans to make this a national priority. Transition: Closing the gap between child and adult services can be accessed at: http://bit.ly/1d7iEOs. Case study 2 demonstrates some of the issues that CYP with diabetes can face in adolescence.

Emotional health and coping
Emotional health is challenged during adolescence and even more so in the presence of diabetes. Depression and other emotional problems have a prevalence rate of 15–20% in people with diabetes (Barnard et al, 2012) and this has an impact on glycaemic control and can potentially lead to DKA. Reliable and validated tools such as “Problem Areas in Diabetes” (Polonsky et al, 2005) have been adapted for adolescents (Weissberg-Benchell and Antisdel-Lomaglio, 2011) and can provide insight into the presence of “diabetes burnout”. A parenting style which supports gradually increasing independence whilst maintaining clear boundaries regarding serious matters such as DKA is advocated (Court et al, 2008) but this may need to be renegotiated during adolescence.

Eating disorders
Food plays a significant role in our lives and, for those with diabetes, the impact of this intense and focussed relationship can cause additional burden.

Case study 2: Teenage girl with diabetes
Amy was diagnosed with type 1 diabetes at 6 years and is now almost 15 years old. She has been on multiple daily injection therapy for the last 8 years. Following several years of excellent control (HbA1c <38 mmol/mol) and good family teamwork, Amy’s HbA1c has now been consistently above 69 mmol/mol for almost a year and had recently risen to 76 mmol/mol.

Today Amy is unwell so her mother phones the out-of-hours service on the designated CYP diabetes ward and explains Amy seems to have a virus like her brother and has now started vomiting. Blood ketones are 3.1 mmol/l and blood glucose 22 mmol/l, therefore the nurse advises to go to the emergency department promptly. Intravenous insulin is prescribed according to the BSPED (2009) DKA protocol. An in-depth clinical assessment is carried out immediately and continued over the next few days, including review of insulin doses (according to weight and age), injection sites and technique, carbohydrate counting, blood glucose monitoring and targets, and hypoglycaemia and hyperglycaemia management.

The next morning the specialist nurse listens to Amy and her family’s story regarding events leading up to the admission. Amy is quiet and difficult to engage. She states whatever she does her blood glucose is always high. Amy’s mother explains that Amy has been reluctant to test her blood glucose and take her insulin for a while now, often justifying that she is not hungry and will do it when she eats later. This has been causing conflict at home as Amy feels her mother is constantly nagging. Amy starts to open up and tells the specialist nurse that she does not see the point of going to clinic as it is boring and does not fit into her life. She says the doctor talks to her mostly and when he does speak to her it is as though she is a young child. Mum is very tearful and tells the nurse that she does not know what to do.
“A comprehensive MDT, which includes a psychologist, can support in-depth assessment of emotional as well as physical health from diagnosis”

Follow up after discharge

Maintaining contact following discharge from hospital, whether newly diagnosed or with existing diabetes, is important and can provide timely support. This support should include practical advice, such as insulin dose adjustment, as well as proactive education and important emotional care.

Conclusion

Prospects are now ripe for improved health outcomes for CYP with diabetes. A comprehensive MDT, which includes a psychologist, can support in-depth assessment of emotional, as well as physical health from diagnosis. Investing in both accredited education and competency-based training opportunities is paramount to ensuring safe, evidence-based care.

Barnard K, Davis N, Taylor C (2012) Implementing psychological assessments required by the Best Practice Tariff for Paediatric Diabetes. Practical Diabetes 29: 335–8
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1. Which of the following should apply to structured education for children and young people (CYP) and their families? Select ONE option only.
   a. Starting at diagnosis and on going
   b. Includes a written document of all education delivered
   c. Based on theory
   d. All of the above

2. According to the paediatric inpatient audit (Edge et al, 2013), how many centres recorded insulin-related prescription errors during admission to hospital? Select ONE option only.
   A. No centres
   B. About half of all centres
   C. Three quarters of all centres
   D. All of the centres

3. The “Safer use of insulin” e-learning module would be suitable for: Select ONE option only.
   A. Healthcare professionals involved in the care of adults only
   B. Inpatient adult and paediatric staff
   C. All healthcare professionals interested in diabetes care
   D. Diabetes specialist teams only

4. According to Peyrot et al (2005), which of the following had the greatest impact on HbA1c levels? Select ONE option only.
   A. When the healthcare professional and CYP disagreed on treatment goals

5. The British Society for Paediatric Endocrinology guidelines for diabetic ketoacidosis (2009) recommends which of the following?
   Select ONE option only.
   A. Insulin to be given without delay
   B. Sliding scale insulin
   C. Continuous infusion of insulin
   D. Regular checks of urine ketones

6. Which of the following ways of preparing a child for an injection is NOT identified by evidence-based guidance in the “First Injection technique recommendations”?
   Select ONE option only.
   A. Use of distraction
   B. Minimal engagement with the child to avoid upset and attention seeking
   C. Cognitive behavioural therapy
   D. Age-appropriate explanations

7. Which of the following statements about injection technique is NOT true?
   Select ONE option only.
   A. Intramuscular injections can result in a more predictable glucose levels

8. What is the incidence of depression in people with diabetes? Select ONE option only.
   A. 25–30%
   B. 20–25%
   C. 15–20%
   D. 10–15%

9. Evidence-based pathways for managing disordered eating in people with diabetes do NOT include: Select ONE option only.
   A. Increase in dietary restraint
   B. Decrease in dietary restraint
   C. Good communication with the multidisciplinary team
   D. Family therapy

10. Which of the following factors are important to ensure high-quality care of CYP with diabetes? Select ONE option only.
    A. A multidisciplinary assessment
    B. Involvement of a psychologist to identify emotional issues
    C. An investment in accredited education and competency-based training for healthcare professionals
    D. All of the above