

Improving health outcomes in children and young people with diabetes: What are the next steps for service improvement?

Despite having one of the most advanced health systems in the world, child health outcomes in the UK are amongst the poorest in Western Europe. Levels of childhood obesity remain high, the UK's mortality rate is higher than comparable countries, and there is significant unwarranted variation in terms of health outcomes across certain conditions and geographical regions. In childhood diabetes, unwarranted variation is well illustrated in both the latest *National Paediatric Diabetes Audit* (NPDA) report (NPDA, 2015) and the *NHS Atlas of Variation* (Right Care, 2014). It can be seen that variation exists across paediatric diabetes units (PDUs) in all regional paediatric diabetes networks across England. The reasons are multifactorial. How services are planned, provided and delivered are obvious factors for variation, but social, economic, self-care management education and less intensive glucose/insulin management are all part of the complex jigsaw.

There are now many publications describing the factors that are associated with improved outcomes in children and young people's diabetes (CYPD). The Hvidoere Study Group studied a number of global paediatric diabetes centres over the last two decades and, in their most recent paper, demonstrated that there was no single factor that accounted for centre differences in HbA_{1c} (Cameron et al, 2013). There were, however, important "non-medical" variables such as "target" setting and effective communication within families that were shown to be strong determinants of metabolic control. Krone et al (2009) describe in detail multiple mechanisms to improve outcomes such as: choice of insulin regimens/analogues; delivery methods; intensive insulin therapy and circadian insulin-carbohydrate ratios from diagnosis; blood glucose testing; and the necessity to adopt a national approach to diabetes self-management education. Swift et al (2010) described the importance of all

members of the multidisciplinary team (MDT) clearly understanding and aiming for lower HbA_{1c} targets. This encouraged the diabetes team to work positively towards achieving the targets with their patients, and each family's perception was of being cared for by a well-functioning team. These important findings emphasise the necessity of MDTs to "all sing from the same hymn sheet". Moreover, sensitivity to cultural and social differences should be high on the agenda (Greene et al, 2002) with an over-arching philosophy of a supportive psychosocial model of care for the child and family (Saßmann et al, 2012; Cameron et al, 2013).

Costs of diabetes

There are very serious consequences for inaction on improving diabetes outcomes. The recent *The Costs of Diabetes* report from Diabetes UK (2014) showed that diabetes accounts for about 10% of the NHS budget, and 80% of these costs are due to complications. The most comprehensive analysis to date concludes that the cost of diabetes to the NHS was £9.8bn in direct costs in 2010/11, with £1bn for type 1 diabetes and £8.8bn for type 2 diabetes. Clearly, the ultimate aim of our treatment for CYPD is to prevent these costly complications and ultimately improve quality of life and well-being, and avoid premature death.

Importance of optimising care processes

The need to optimise care and outcomes is directly related to morbidity and mortality data in young people with type 1 diabetes. It is well accepted that poor glycaemic control is strongly linked to both micro- and macrovascular complications, with metabolic memory from pre-pubertal CYP playing a crucial role (McNally et al, 1993; The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2000). Mortality data show the commonest causes of death under the age



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of 30 years to be diabetic ketoacidosis (DKA) and hypoglycaemia. At the opposite end of the spectrum, good glycaemic control has been linked with improved quality of life and well-being (Hoey et al, 2001; Mazza et al, 2014).

The effects of broader sociological and educational issues should not be ignored. There is increasing evidence that age, gender, poor glycaemic control, comorbidities, clinic non-attenders and the existence of psychological problems in the individual with diabetes are strong indicators of the risk of developing DKA (Wright et al, 2009). Targeting young people who are particularly at risk may also improve outcomes, as around a quarter of admissions for DKA are in the 16 to 25-year-old age group. In adults with type 1 diabetes over the age of 30 years, the cause of death is likely to be vascular disease. In this regard, it is essential that every opportunity is taken to optimise glucose control, normalise lipid levels and blood pressure, and offer routine screening for eye disease, kidney function and foot health. These annual care processes have been clearly set out in NICE guidelines (NICE, 2004).

So where are we now?

The recent Diabetes UK report for England, *State of the Nation: Challenges for 2015 and Beyond*, describes how people with type 1 diabetes of all ages and ethnic groups routinely receive poorer care and treatment than people with type 2 diabetes. Treatment targets, recommended care processes, and lack of access and uptake to self-management education (SME) were all highlighted as contributing factors.

The NPDA reports annually on the completion rate of seven care processes that CYPD should receive in England and Wales. In their most recent report (NPDA, 2015), data was collected in audit year 2013/14 from 26 598 CYP. Almost all (98.3%) had at least one HbA_{1c} measurement in the audit period. However, only 16.1% of children aged 12 years and older received all seven recommended care processes (i.e. HbA_{1c}, body mass index, blood pressure, cholesterol, urinary albumin, eye screening and foot examination), compared to 12.1% in the 2012/13 audit period. Mean HbA_{1c} was 71.6 mmol/mol (8.7%), falling from 73 mmol/mol (8.8%) in 2012/13. In 2013/14, 18.4% of CYP had an HbA_{1c} <58 mmol/mol (<7.5%) and 23.9% had an HbA_{1c} >80 mmol/mol (>9.5%)

compared with 15.8% and 25.9% in 2012/13. Despite some improvements in care processes and outcomes, we have a very long way to go to match the performance seen in other European countries. Completing and recording these care processes can highlight complications at their earliest stage, allowing action to be taken to reduce the risk of complications progressing with the associated risk of reduced life expectancy.

How can we improve our care processes to improve outcomes?

The NPDA is a powerful tool for measuring performance and it reports on the delivery of a high-quality system of care based on standards set by NICE. It is essential that the NPDA findings be used by clinical teams to drive improvements in the diabetes services they provide for their patients and families. The findings can also be used by regional diabetes networks, CCG commissioners, patients, parents/carers and policymakers to set priorities for CYP's diabetes care.

Improvements in care have also been encouraged by the introduction of the Best Practice Tariff (BPT) in 2012 (Department of Health, 2013). PDUs should be working towards providing diabetes services according to the minimum standards set out in the BPT and ensuring that this tariff is spent in a way that allows the PDUs to deliver high-quality diabetes services to children and families, and is measured by annual improvements in outcomes.

In 2013–14, the National Paediatric Diabetes Peer Review Programme (NPDPRP) completed a comprehensive review of PDUs across England and Wales. Each PDU had to self-assess against a set of “measures” and produce an operational service plan, an annual report and service improvement plan. A peer-review team subsequently visited each team and an individual unit report was prepared. Sharing good practice was encouraged. A national overview report of the NPDPRP is in press.

The introduction of these quality-improvement initiatives cannot be expected to result in marked changes in outcomes immediately. Gerstl et al (2008), using longitudinal population data from Germany and Austria, demonstrated a gradual reduction in HbA_{1c} over a decade. It is important, therefore, that we continue to maximise the benefits of having a high-quality annual audit, a BPT to support the provision of services and a quality surveillance programme well into the future.

The contribution of self-management education in improving outcomes

JDRF's *Type 1 Diabetes Research Roadmap* (JDRF, 2014) identified self-management education (SME) as a key issue in the care pathway of all people with diabetes. Particular barriers and challenges that face CYP and their families were identified. The All-Party Parliamentary Group (APPG) for Diabetes has built on these findings and recently published their report *Taking Control: Supporting people to self-manage their diabetes* (APPG for Diabetes, 2015). The report, supported by Diabetes UK and JDRF, includes the thoughts of a wealth of stakeholders, including the feelings of young people and parents about the diabetes education that they receive. The report calls for a shared approach from all stakeholders to produce a national package of education, specifically for CYP and their families that is kept up-to-date and is quality assured to assess the effectiveness of the programme. International guidelines and recommendations (SWEET Project EU, 2012a; ISPAD, 2014) and the BPT call for a structured approach to SME. We also need to learn from the findings of randomised controlled trials in the education of CYP and families (Waldron, 2012) and our European colleagues (SWEET Project EU, 2012b). Bringing the expertise of all stakeholders together to produce a national age- and maturity-appropriate education programme will provide a minimum standard of education, reduce variation and also reduce the necessity for individual MDTs across the country to constantly produce their own education curriculum and teaching materials.

The future

It is important that collaborative working between all stakeholders, including the National and Regional CYP Diabetes Networks and the Families with Diabetes National Network, goes from strength to strength. Partnership working is critical in our success in identifying and prioritising new approaches to improving the quality of our diabetes services. We must continue to do everything we can to improve outcomes to ensure the future health and well-being of our children and young people with diabetes. ■

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