

Media hype: What effect does it have on diabetes management for children and young people?

One would be forgiven for thinking that a miracle development and potential cure for diabetes is just around the corner with the media headlines full of promise that “the bionic pancreas really works” and “breakthrough offers hope ... a cure for diabetes”. Whether such headlines are helpful, giving hope to people with diabetes, or morally bankrupt, preying on the hopes and fears of people living with this condition every day, is a different matter, but they do highlight both the urgent need for a cure and the exciting progress in technologies that are currently available and in development.

New technologies include sensor-augmented insulin pump therapy, low blood glucose suspend technology, overnight closed loop and fully automated artificial pancreas, all of which are looming ominously on the horizon. Usability, technology interface, accuracy and size of devices are improving with each new generation; although when it comes to continuous glucose monitoring (CGM), there is clearly still room for improvement. The emphasis on new technologies is placed on ever-improving engineering and tighter glycaemic control, with the psychosocial impact often overlooked (Oliver et al, 2014).

A different focus

Sub-optimal glycaemic control among children with diabetes remains widespread despite current insulins and devices capable of far greater control than the statistics suggest, so it seems odd to blindly focus on the technology itself rather than explore the reasons why people are unable to achieve their treatment goals. The personal barriers to optimal diabetes control simply won't go away with more advanced technology. What is really needed is a shift in the focus of device development to address some of the common barriers to usage (e.g. false alarms, lack of accuracy), and actually to incorporate some of the more “lived experience” facilities that people with

diabetes ask for. Critical to this is incorporating several devices into one piece of equipment that is sufficiently small and discreet to avoid drawing attention to a person's difference simply due to having diabetes.

Continuous knowledge of glucose levels with an accurate discrete device has been cited as a research priority by people with type 1 diabetes (Gadsby et al, 2012), but CGM has received mixed reports in the research (Tansey et al, 2011; Mauras et al, 2012). Improvements in glucose control are dependent on regular use, but this is expensive with sensors costing around £50 each and lasting on average 6–7 days. Furthermore, alarm fatigue, technical failure and accuracy problems limit ongoing engagement, with lack of trust in the devices and irritation with technological failure being the primary reasons. A negative psychosocial impact of CGM has been described previously (Markowitz et al 2012), and, despite a high proportion of pump use, CGM use in the T1D Exchange cohort remains low at 6.5%, with two-thirds of those commencing CGM subsequently stopping it (Wong et al, 2014).

The bombardment of well-meaning but premature promise on the internet and in the media requires the need to manage the expectations of those with diabetes. The reality is that the artificial pancreas is not available, nor will it be so for a number of years. Insulin pump therapy is recommended by NICE (2008) as a therapy choice for children up to the age of 12 years; however, CGM is not commonly reimbursed and thus unavailable for most children. Even if it were available, as shown by the research, there is mixed evidence of benefit.

Family matters

Perhaps one of the most exciting developments in the management and support of children and families living with diabetes is the introduction of the Best Practice Tariff (Randall, 2012). This sets out a benchmark for minimum standards of care in paediatric diabetes, which includes annual



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psychological screening for children. Sadly, the psychosocial needs of parents remain unaddressed. Routine screening for parents could provide an opportunity for healthcare professionals to glimpse the reality of the burden of daily living with diabetes, and the particular stressors and psychosocial barriers to optimal diabetes management. Perhaps this will come next.

When considering the dynamic that exists between healthcare professionals and families, it is important to remember that there exists an inherent power imbalance in clinics that is not conducive to optimal communication. Mostly, parents require empathy (not sympathy) from clinicians that managing their child’s diabetes is a difficult challenge, with understanding that it’s hard work and relentless. A dialogue that is supportive rather than traditionally paternal in consultations and contacts with healthcare professionals is important. Currently, these things are not commonplace and many parents anecdotally feel that going to clinic is an ordeal, rarely useful and mostly involves being “told off” or spoken to in a way that infers that they are not trying hard enough to manage their child’s diabetes.

Accessing the best paediatric care

So how do we ensure that the people who will benefit most from new technologies (such as CGM and insulin pumps with low blood glucose suspend) and rapidly developing research into artificial pancreas technologies are able to access these opportunities? Providing sufficient information about technology options in ways that are appropriate for each family and then ensuring that families have sufficient time to be able to carefully consider the benefit and disadvantages of each option are crucial.

The Best Practice Tariff is a step towards this; however, there is no consistency in how psychosocial assessments are conducted or who should be responsible for doing so. Furthermore, a failure to address parental psychosocial distress may simply result in moving the barriers rather than overcoming them. In truth, what person-centred care means on a practical perspective remains opaque.

Routine structured education for children with diabetes is currently not provided. A number of large multicentre randomised controlled trials have taken place in this regard over the past few years, yet none of them have fully achieved their primary objective of improving HbA_{1c} (Gregory et al, 2011;

Robling et al, 2012; Christie et al, 2014). This perhaps reflects the reality that HbA_{1c} may not be the right measure. All of the trials showed a benefit in various aspects of psychosocial functioning. It is exceptionally difficult to power a trial on a psychosocial outcome and funders are reluctant to support a trial that is outside of their traditional scope. Yet, a shift away from a purely traditional model to a more holistic, person-centred approach has long been advocated. A collaborative approach by individualising care with the person with diabetes at the heart of decision-making is key (Funnel, 2006). The Institute of Medicine (2001) stated that it is important to “[provide] care that is respectful of and responsive to individual patient preferences, needs and values, and [to ensure] that patient values guide all clinical decisions”.

The National Service Framework (Department of Health, 2001) aimed to ensure that people with diabetes were empowered to enhance their personal control over day-to-day diabetes management in a way that enabled them to experience the best possible quality of life. NICE also recommended that all service developments should be needs-led and the psychological needs of people with diabetes should be addressed in an organised and planned way (NICE, 2003; 2004; 2010). Perhaps now is the time for research funders to broaden their remit and accept that psychosocial aspects of disease are important outcomes in their own right.

We need to be able to objectively demystify the potential benefits and downsides of technologies, and explore the impact on the lived experience of people with diabetes. The reality of NHS healthcare is that rationing does exist and every decision has to be made with a cost–benefit analysis in mind. Being open about the strengths and disadvantages of technologies would help in this regard. It would be easier for families to make informed decisions about whether or not a given device might be suitable for them and facilitate a patient-centred discussion about alternative options. In turn, this could help people turn away from the media hype and recognise it for exactly what it is ... hype. ■

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