The challenge of improving outcomes in young people with type 1 diabetes

Simon Heller, Jackie Elliott and Christine Eiser on behalf of the Collaboration for Leadership in Applied Health Research and Care, South Yorkshire diabetes theme

Type 1 diabetes is perhaps at its most challenging during adolescence, when individuals are expected to take control of their condition. Despite the development of new insulins and modern technology such as blood glucose monitoring and insulin pumps, glycaemic control is generally poor in young people with diabetes, which can result in microvascular damage and long-term complications. This article highlights the difficulties experienced by young people and the hurdles that face individual units in trying to improve outcomes for this vulnerable group. The authors describe a complex intervention that they hope will contribute to improved clinic attendance and health outcomes for young people with diabetes, in collaboration with their families and professional carers. This approach will be trialled across other units to determine its successs and cost-effectiveness as a care model.

Although the discovery of insulin over 90 years ago dramatically reduced mortality in people with type 1 diabetes, the condition remains demanding for those affected, their families and the healthcare team. Despite the development of new insulins and modern technology such as blood glucose monitoring and insulin pumps, type 1 diabetes is perhaps at its most challenging during adolescence. Although the transition from childhood to adulthood is a period when individuals are particularly expected to take control of their condition, surveys have consistently shown that blood glucose control is worse in this age group compared with in younger children (Bryden et al, 2003; Helgeson et al, 2008). This is particularly worrying because raised blood glucose levels at this time appear more likely to cause microvascular damage, resulting in long-term complications such as retinopathy, neuropathy and nephropathy (Marcovecchio and Chiarelli, 2011). The development of diabetic kidney disease also accelerates ischaemic heart disease and reduces both the person's quality of life and longevity. In addition, there is a huge economic burden placed on treating individuals with complications that has to be paid by the NHS and thus wider society.

The consequences of poor biomedical outcomes have been emphasised with the publication of the *National Diabetes Audit Mortality Analysis 2007–2008* (NHS Information Centre, 2011), a comprehensive review of outcomes in people in England with different types of diabetes across a range of ages. The audit used coding data to establish mortality rates in those with diabetes compared with the background population without diabetes. Perhaps the most startling finding was an increased mortality among those aged 15–30 years with diabetes, which was nine times higher in young women with diabetes and four times higher in young men with diabetes than those without diabetes. These worrying data probably reflect

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Article points

1. During the transition from childhood to adulthood, young people with type 1 diabetes have to take control of their condition; however, glycaemic control is generally poor in this age group.
2. Although the reasons for poor glucose control in young people with diabetes is multifactorial, a key component is their difficulty in undertaking and sustaining successful diabetes self-management.
3. The authors have developed a complex intervention, including structured education, improved communication by healthcare professionals, a better clinic environment and intensive support for families, to provide a successful and cost-effective model of care.

Key words

- Complex intervention
- Diabetes self-care
- Transition clinics

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"Perhaps the most important factor that predicts poor blood glucose control among this age group is the difficulty that most young people experience in undertaking and sustaining successful self-management of their condition."

ineffective self-management among young people, and a resulting onset of complications of diabetes with downstream increases in mortality.

A need for change

The importance of focusing on this age group has been recognised by the provision from the Department of Health for an increased tariff providing more generous financial support compared with previously (NHS Diabetes, 2012). This includes the greater requirement for dietitians, structured education and access to psychological help. However, it is a dangerous over-simplification to assume that merely providing more of the same care will necessarily lead to better outcomes. Although greater clinical provision is important, in the authors' unit they have reflected on these issues and have concluded that there needs to be a much more fundamental review of requirements for these vulnerable people and a more thoughtful way in which support is developed and evaluated.

The authors' existing transition clinics for young people aged 16–21 years are informal and multidisciplinary, and include healthcare professionals from both adult and paediatric units. Appointments are generally offered at 3-monthly intervals, and parents (and friends) are encouraged to attend. Diabetes nurses and dietitians from both services are ready to see young people informally and provide extra input in addition to clinic visits; the authors also have access to specialist psychology services. Yet, however user-centred, both the high levels of HbA_{1c} and "did not attend" rates suggest that this approach, based around traditional clinic visits, is often ineffective; other approaches are therefore needed.

The reasons for poor glycaemic control in this age group are multifactorial. Altered hormonal levels during puberty appear to lead to insulin resistance and a more rapid tendency to develop ketoacidosis (Acerini et al, 2001). Young people themselves have rarely been formally taught the skills of self-management but have picked these up from their parents, who were inevitably the focus of education around diabetes management. However, it is not simply a matter of providing skills training to these young people; perhaps the most important factor that predicts poor blood glucose control among this age group is the difficulty that most young people experience in undertaking and sustaining successful self-management of their condition (Helgeson et al, 2008). Furthermore, although the reasons are unclear, there is evidence that glucose control among young people with type 1 diabetes is worse in the UK than in other European countries (Danne et al, 2001).

Type 1 diabetes is an almost unique condition in that the success of treatment depends not upon the skills of the medical and nursing team but on the ability of young people with diabetes to manage their illness successfully. The demands on people with type 1 diabetes are especially challenging if they are to reach and maintain recommended glucose targets to minimise the chances of developing tissue complications. It requires the calculation of the correct insulin dose, taking into account the prevailing blood glucose, the amount of carbohydrate being consumed, the likely level of activity and the effect of any alcohol consumed; these actions need to be repeated each day, at least before every meal (Heller, 2011).

The intensity of self-management imposed on individuals is also compounded by the side effects of treatment. Thus the limitations of both subcutaneous insulin therapy and the current methods of blood glucose measurement present additional barriers to those who strive to keep their blood glucose close to normal. They run a high risk of hypoglycaemia and are more likely to gain weight. It is unsurprising that so many individuals struggle to achieve and sustain self-management at this level of intensity. These demands are particularly challenging for teenagers and young adults who are already trying to cope with the pressures of adolescence itself.

Development of a complex intervention

The causes of high levels of glucose and the consequent danger of associated complications are multifactorial, which means that the solution is unlikely to rest with a single intervention that will magically improve the attitude and approach of these young people. The authors have concluded that what is needed is a complex intervention that would incorporate a number of components, such as:

- A structured education course.
- Improved communication skills among healthcare professionals.
- A better clinic environment.
- Intensive support for families at critical times.

However, none of these components are likely to work in isolation; indeed, the authors believe that it would be a mistake to develop and test a single, relatively simple intervention. There is a danger that an intervention implemented and evaluated in isolation may be deemed ineffective, yet have considerable potential to contribute positively if delivered within a package of measures.

The authors based the development and evaluation of their intervention for young adults in the transition clinic around guidelines published by the Medical Research Council (Campbell et al, 2000). These advise developing the components of the intervention in a series of phases, although these are not necessarily undertaken in a strict time order (Craig et al, 2008). They suggest using underlying psychological theory to underpin one or more of the components, followed by a modelling phase in which the different components are developed, piloted and modified. The third phase consists of relatively small-scale feasibility/pilot trials culminating in a definitive, randomised controlled trial. The intervention is finally systematically evaluated during roll-out in large-scale observational work in which the results in other centres are compared with those observed during the original trial.

To inform the development of the authors' interventions they have sought the views of young people attending their transition clinic as well those of parents and healthcare professionals (Brierley et al, 2012); all three groups expressed dissatisfaction with the current service. Some healthcare professionals reported they lacked confidence to work with the age group, were unsure about how colleagues approached problems, and experienced difficulties in that colleagues differed in their views of young people and, critically, in their approach to management. These views were reflected by young people; they disliked seeing different healthcare professionals on different occasions, who often gave conflicting advice with goals negotiated at one appointment not followed through at subsequent visits. Parents wanted a clearer and more defined role, and to be informed of changes made to the young person's care. Both healthcare professionals and parents emphasised that young people had unique needs, necessitating a holistic and individual approach to education and management.

Based on a literature review, the authors identified relatively little research that specifically addressed the needs of young people, with most focusing on paediatrics and the transfer to adult-based care. The role of healthcare professionals appears critical; where they adopt a consistent approach to care, HbA_{1c} is generally better compared with units where the team adopt different approaches to management (Swift, 2009). The data confirm that glycaemic control is generally poor in young people with diabetes, and typically worse than that in children (Anderson et al, 1997). The position regarding mental health is less clear, although poorer mental health is clearly a risk factor for clinical depression in this group, as is the case with adults (Johnson et al, 2012).

Elements of the authors' approach include:

- A self-management skills training course underpinned by constructivist learning theory (Hoover, 1996) specifically designed for this age group – WICKED (Working with Insulin, Carbs, Ketones and Exercise to manage Diabetes).
- A targeted communication course for parents to help them provide constructive support for their children.
- Communication skills training for the whole professional team.
- A joint goal-setting approach to increase self-confidence for young people to manage their self-care.

The authors have also made changes to the clinic organisation and process to provide greater consistency during consultations and facilitate the move of young people from the paediatric to the transition clinic. Baseline assessments of biomedical and psychosocial outcomes will be repeated as the authors incorporate the different components of their new approach to evaluate the effectiveness of the total package.

The ultimate aim is to develop an individualised programme for young people with diabetes, with their families and healthcare professionals working collaboratively to provide solutions that are appropriate for them at that time. The authors are currently using qualitative and quantitative approaches to model and pilot the different components of their intervention. The work involves a large multidisciplinary team consisting of clinicians, including nurses and dietitians, health psychologists, project management and administrative support. The authors are grateful to be able to use funding from the National Institute for Health Research (NIHR) Collaboration for

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Leadership in Applied Health Research and Care, South Yorkshire (CLAHRC SY), to initiate this project.

The way forward

The authors hope that a more coordinated and thoughtful approach to diabetes self-management, which places young people and their families in a central role and which acknowledges their individual needs, will prove to be more successful and cost-effective than current care models. They also hope to demonstrate that such an approach is generalisable beyond a few centres that can access additional resources. To this end the authors plan to undertake feasibility/pilot work in units with a range of facilities and healthcare professionals, and acknowledge that any definitive trial would also need to be conducted in different NHS settings. Nevertheless, the additional monies that accompany the new best practice tariff for paediatric diabetes could enable a more effective care model to be provided from existing resources. ■

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