Developing structured education for young people with diabetes

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Structured education for children and young people with diabetes lags behind that developed for adults. The Department of Health (DH) and Diabetes UK (2005) outlined a set of key criteria that an educational programme should fulfil; yet, despite several good examples of structured education for young people – such as Kick-Off (Kids in Control of Food), FACTS (Families, Adolescents and Children's Teamwork Study) and StEP (Structured Education for Pumps) (Diabetes Education Network, 2008) – there are still no nationally available programmes, and only 26% of this population have attended a course to learn about their diabetes (Diabetes UK, 2010).

Paediatric diabetes care teams are often small, with part-time staff struggling to manage their ever-expanding case loads (Royal College of Paediatrics and Child Health, 2009). The paediatric DSN is often the only team member solely designated to the role, with other members only commissioned for enough sessions to cover clinics. Structured education is therefore difficult – not only to develop, but also to administer – and is hence not afforded the priority that it should. If commissioners and healthcare providers could negotiate locally agreed tariffs then maybe education programmes could be given the priority they deserve (DH, 2007).

Recruiting young people into structured education may be difficult if the young people do not see it as a priority, and age banding of groups is a necessity as there is a wide variability of social and emotional development in the different education key stages. There is also the practicality of when to run these sessions as many young people may not wish to give up evenings or weekends. This barrier to attendance may not only come from the individuals and their families, but also the paediatric teams having to undertake this as additional duty.

It is important that whatever structured education programme is developed meets the needs of these children and young people, and their families. Managing diabetes requires motivation and long-term behavioural change, both by the young person and his or her family. It is therefore interesting that programmes such as Kick-Off and CHOICE (Carbohydrate, Insulin Collaborative Education) attempt to provide the education programme to the young person alone, despite evidence for the need for parental involvement to assist in regimen adherence (Ellis et al, 2007).

People live in dependent relationships where they rely upon others to motivate and support themselves. Many children and young people in the age range for these programmes still live in the family home and are not be responsible for day-to-day shopping and cooking. Social learning theory emphasises the importance of modelling (Bandura, 1977), and by families sharing the learning experience and developing a meaningful narrative while practising their new skills, sustained behavioural changes are more likely to occur. It is therefore important that all those delivering educational programmes should facilitate such dialogue.

We must also acknowledge the fears and practical difficulties encountered by young people when being asked to make dose decisions, and we must foster ways of gaining support and collaboration from their families. In their article on page 370, Chaney et al (2010) consider the impact of poor numeracy skills and parental reluctance in letting their children adjust their own insulin, but we must also enable people to explore their fears about "getting it wrong" and provide opportunities to explore all the "what ifs".

For many people, dose adjustment may seem like a science, but it is important to emphasize that it can be more of an art, where not all the variables can be controlled. Individuals can only "control the controllable" and must learn the skill of problem-solving and use all the resources available to them, including help from others.

Programmes currently in development, such as CASCADE (Child and Adolescent Structured Competencies Approach to Diabetes Education; Christie et al, 2009) appear to emphasise a more psychological approach, which should motivate and deliver long-term change. This, along with the SWEET project – which hopes to draft recommendations for education programmes (Diabetes UK, 2009) – may at last provide the structured education needed for this population. ■