

Structured patient education to improve self-management: A vision for the future

For over a decade, national and international clinical practice guidelines from paediatric diabetes associations have widely accepted the need for age-appropriate, individualised, quality-assured, structured patient education (SPE). However, despite this, SPE for children and young people (CYP) with diabetes and their families and carers has only more recently received the attention it deserves and is not fully integrated into routine clinical practice. Our national guidance describes the criteria for the development of an SPE programme (NICE, 2004; Department of Health and Diabetes UK, 2005), whereas the International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines (Swift, 2009) give the most comprehensive and detailed descriptions and recommendations. ISPAD provides in-depth information on: the practice of age-related education; guidance on varying aspects of education; organisational principles; detailed curricula at different ages and stages of diabetes; and recommendations on models, methods and tools to attain educative objectives. Clear guidance is also given from the International Diabetes Federation (IDF) Standards for Diabetes Education (IDF, 2009) to guide the development and continued improvement of diabetes self-management education and support. In addition, one of the 13 criteria of the paediatric diabetes Best Practice Tariff (BPT) (Randell, 2012) states that:

“Each provider unit must provide evidence that each patient has received a structured education programme, tailored to the child or young person’s and their family’s needs, both at the time of initial diagnosis and ongoing updates throughout the child or young person’s attendance at the paediatric diabetes clinic.”

Even though all these detailed guidelines exist, there are still no national evaluated and accredited SPE programmes for CYP with diabetes at different ages (less than 5 years, primary, secondary or young

people in transition). Moreover, there is no national programme for parents, siblings, grandparents and extended carers that deal with age-specific guidance for living with a child with diabetes. A national programme could aid transferability of SPE programmes between centres, enhance consistency and facilitate the development of a quality assurance programme. At the present time, each individual multidisciplinary team (MDT) develops localised SPE programmes and this leads to the profound diversity of practices demonstrated by the SWEET EU Project (Martin et al, 2012) in terms of organisation, practices, the content of initial and continuing education, and lack of evaluation. Prior to the introduction of the BPT, it is reasonable to suggest that SPE programmes were seen as less important when compared to treatment regimens (Martin et al, 2012; Juvenile Diabetes Research Foundation, 2013), and this is highlighted by a very practical example of having no suitable rooms/areas available for educational activities. The introduction of the BPT and the Paediatric Diabetes Peer Review quality assurance programme (NHS Diabetes, 2012) have highlighted the necessity to embed SPE as an equal component of high-quality care with a clear quality-assurance measure which states that:

“The paediatric diabetes MDT should have a policy whereby each patient is offered a diabetes self-management education programme at the time of initial diagnosis and ongoing updates throughout the child or young person’s attendance at the paediatric diabetes clinic. The programme should be tailored to the individual needs of the child or young person taking into account age and maturity and should:

- have a structured, written curriculum
- have trained educators
- be quality assured
- be audited.”

Specific national guidance pertaining to the



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optimal management of diabetes in schools is also being developed at the present time and this was described in detail in the previous edition of this journal (Campbell and Waldron, 2013).

The evidence to date is very clear that, along with the core components that are necessary to deliver high-quality, structured, family-centred education, an MDT with paediatric diabetes experience and expertise, and that includes a psychologist, is essential (NICE, 2004; Swift, 2009; Waldron et al, 2012). The IDF (2009) also highlights the importance that MDTs have to demonstrate “an effective communication system” that ensures that education information is shared “formally” and that all team members “sing from the same hymn sheet”. King et al (2013), in the previous edition of this journal, describe clearly the necessity to have adequate numbers of experienced MDT members, defined treatment targets for the team and families, coordinated management plans, and clear communication and consensus between all team members and the family if optimum glycaemic control and quality-of-life outcomes are to be met. It is also now widely accepted that optimising glycaemic control from the first day of diagnosis is essential, as this will influence the phenomenon known as “metabolic memory”, and will decrease the risk of diabetes complications in later years. Consequently, an individualised approach to self-management education is essential from the day of diagnosis. It is now considered essential that every person with diabetes has their ability to self manage their condition assessed on a regular basis. Cooper et al (2014) describe an individual needs assessment tool for young people and their self-management education; the emerging results show promising improvements to diabetes outcomes.

It is also important that education is not just seen as imparting knowledge or intensifying therapy by escalating pharMO-technology at the expense of other aspects of management.

Skinner and Cameron (2010) suggest that prime issues appear to be philosophy of care, team cohesion, goal-setting and psychosocial support/evaluation to support the individualised self-management care plan. The Hvidoere International Study Group on Childhood Diabetes also support this view and, after two decades of trying to find the reason for centre differences in glycaemic control, they suggest that “non-medical” variables are strongly associated with metabolic outcome,

such as adopting a treat-to-target approach and effective family communication. The Hvidoere Study Group (Cameron, 2013) concluded that it appeared that therapeutic strategies alone would not obtain desired clinical outcomes and it was the underlying therapeutic philosophy, based on a qualified common training for all team members delivering diabetes care and education to the families, that drove improvement. Lange et al (2007a) describe clearly the prerequisites of high-quality, structured, family-centred education for type 1 diabetes that is based firmly on a psychosocial model.

It is now well recognised that the core knowledge, skills and competency levels of our workforce should be clearly defined. Accredited training is mandatory in some of the European Union states (Waldron et al, 2012) and so, as we move towards developing a clear career pathway for healthcare professionals (HCPs) in the specialty of CYP diabetes, perhaps mandatory training should be introduced into our workforce too. We do need to address the notable shortfall in our current training in psychosocial, age-appropriate stages of education and coping strategies, and in how best to psychologically support all families to live with a long-term condition such as diabetes. Advocates for improving self-management education, such as the IDF Youth Charter (IDF, 2007) and the DAWN Youth Call to Action programme (DAWN Youth, 2009), have long since highlighted the critical importance of full integration of psychological and social aspects in paediatric diabetes care and education, with an ongoing process for the provision of individualised self-management and psychosocial support. As a consequence, embedding pedagogy into HCP training is now a priority and has been successfully taken forward by some UK universities (e.g. patient-centred/psychosocial management modules, teaching skills courses and the most recent development of an Advanced Diabetes Educator in Paediatrics Diabetes Master’s course). There is also a need to improve our regional education programmes to ensure that all HCPs can have equal opportunities to access high-quality training. We can also learn from what colleagues in other EU countries have done. In Germany, the German Diabetes Association (Lange et al, 2007b) has recognised over the last three decades the need for HCPs not only to be clinically competent, but also to be skilled in the art of family-centred, self-

management education. From that point onwards, active pedagogy was embedded in the training of all HCPs that care for children and families with diabetes, and the profession of the Certified Diabetes Educator was realised.

To date, there is still no consensus on the evaluation of educational programmes in the UK, which is also in keeping with many SWEET centres (Martin et al, 2012). Diabetes centres use various methods to assess knowledge, skills, behaviour and attitudes, as well as psychosocial factors, such as quality of life, mental health, service satisfaction and support from family and school, with very few centres reviewing their programmes in relation to outcomes. These findings suggest that evaluation is not fully integrated into the routine of diabetes education, and there is scope to establish common national and international evaluation tools that are benchmarked against outcomes to improve education standards.

In the first instance, we should attempt to come to a national consensus as to what we think is the most appropriate structure and organisation for an individualised family-focused education programme that has an agreed evaluation of the programme, validated education tools and clearly defined outcomes measures. It is essential, in order for this initiative to be successful, that we introduce the plan at diagnosis and continue it throughout a patient's journey with diabetes. ■

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