

Challenging diabetes during adolescence.

A case study

Julie AB Edge

Type 1 diabetes is a complex condition that requires a great deal of careful management. For an adolescent, it can be even more testing and deterioration in control during this period is common. This case study illustrates the impact that diabetes had on a 14-year-old boy and how adolescence may have affected the self-management of his condition. It also explores the complexities of family dynamics and the support that they and the school can provide as “significant others”. A broad family assessment of health and social needs is recommended in cases like this, so that support can be tailored to needs.

Type 1 diabetes is a lifelong, chronic condition and the most common endocrine disorder of childhood (Edge et al, 2013) with a peak onset during adolescence (SEARCH for Diabetes in Youth Study Group et al, 2006; Jaser et al, 2012). This complex and relentless condition requires a great deal of management in a young person, including numerous blood glucose checks and the calculation of insulin-to-carbohydrate ratios, in order to meet the desired HbA_{1c} target of <58 mmol/mol (<7.5%; NICE, 2004). McNamara et al (2011) stressed the importance of recognising that diabetes also directly impacts on a child or young person’s family, culture, school and their peers, challenging their ability to manage this condition.

Significantly, adolescence is a critical time when deterioration in diabetes management is common (Hamilton and Daneman, 2002; Hilliard et al, 2013). Numerous studies confirm the risks these young people face growing up and discuss how health professionals can work in partnership to promote diabetes self-management and knowledge acquisition.

The following case study illustrates the impact that diabetes can have on an adolescent’s life and their ability to manage their condition. It explores the importance of “significant others”, such as

parents and school, as protective or risk factors that can enable or prevent effective care.

The case study

Felix (a pseudonym) was diagnosed with type 1 diabetes at the age of 14 years, 6 months ago at the time of writing. He lives with his mother (a single parent) and 10-year-old sister. Felix embodies many of the challenges faced by adolescents with this condition, and the difficulties families and professionals face when involved with this age group. Young people may not be fully engaged with the aims of their diabetes care owing to other factors in their adolescent lives (Funnell and Anderson, 2004).

The Common Assessment Framework

Woolston et al (1998) argued that when working with adolescents within a health context like diabetes, the principles for interventions should be family focused. The Common Assessment Framework (CAF) supports this approach (Department for Education [DfE], 2012; see *Box 1*). As a multiagency document, it also facilitates sharing of information and collaboration in care in agreement with the family and young person. Significantly, it supports a team around the family approach.

CAF was adopted as a tool to understand and

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Article points

1. Adolescence is a critical time of social and cognitive development when deterioration in glycaemic control is common.
2. “Significant others”, such as family members and schools, have an important effect on health outcomes in adolescents with diabetes.
3. In order to provide the resources that a family with an adolescent with diabetes requires, a thorough assessment of their health and social needs should be carried out.

Key words

- Adolescence
- Glycaemic control
- Parental support
- Type 1 diabetes

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Box 1. The Common Assessment Framework.

The Common Assessment Framework is a standardised approach to the assessment of children and their families in order to facilitate the early identification of additional needs and to promote a coordinated service response (Department for Education, 2012: p. 44).

evaluate the difficulties that Felix and his family were facing with his diabetes management, and how they could be best supported.

Case background

Approximately 30% of children who present with newly diagnosed type 1 diabetes are ill with diabetic ketoacidosis (DKA; NICE, 2004). Symptoms of weight loss and tiredness are commonly mistaken for the effects of puberty (Edge et al, 2013), resulting in very acute stages of DKA on admission. Felix was acutely unwell at diagnosis and required intensive management following the DKA pathway to stabilise his condition (NICE, 2004; British Society for Paediatric Endocrinology and Diabetes, 2009; International Society for Pediatric and Adolescent Diabetes [ISPAD], 2009; Ali et al, 2011).

Felix recovered after 48 hours and commenced subcutaneous multiple daily injections of insulin (NICE, 2004; ISPAD, 2009). On day 4, Felix was competently self-managing his insulin injections in line with a structured educational approach identified in the Best Practice Tariff (BPT; Randell, 2012) that included a basic introduction from the dietitian to carbohydrate counting, the impact of exercise and importance of a balanced diet (ISPAD, 2009; Randell, 2012).

Follow-up support with structured diabetes self-management education from diagnosis is essential in patients being enabled to manage their diabetes (Department of Health [DH], 2005; Lange et al, 2007; ISPAD, 2009). However, Felix's mother identified early on that she felt Felix would benefit by learning to cope on his own and declined additional structured education visits, feeling that they were managing themselves. This was a risk factor for Felix bearing in mind his young age and the level of responsibility being placed upon his shoulders following a life-changing diagnosis.

Consequences of poor glycaemic control

Felix was readmitted less than 3 months after diagnosis with symptoms of DKA and a significant blood ketone level (5.7 mmol/L) that required treatment with insulin correction only, as he was clinically well (ISPAD, 2009; Edge et al, 2013). He said that he felt unaffected by these symptoms, but his mother had noticed he was drinking excessively, had lost weight and was more irritable,

indicating hyperglycaemia and a risk of DKA (Hanas, 2012). Felix's HbA_{1c} had not reduced from 130 mmol/mol (14%) since his diagnosis. Results from the National Paediatric Diabetes Audit (2012) found that only 17.4% of children meet the HbA_{1c} target of <58 mmol/mol (<7.5%; NICE, 2004) with 25% of children having an HbA_{1c} over 80 mmol/mol (9.5%), putting them at high risk of future complications (The Diabetes Control and Complications Research Group, 1993).

Six weeks after his DKA admission, and with no improvement in his condition, a planned admission was negotiated with Felix and his mother to observe his self-management skills and knowledge, and to enable Felix to feel the positive health effects of normal glycaemic levels. This form of management is routinely adopted in neighbouring European countries where 50% of children meet a target HbA_{1c} of <58 mmol/mol (7.5%; de Beaufort et al, 2007; SWEET, 2012). For Felix, this brief interlude of glycaemic control was not sustainable once discharged after 5 days, and questions whether Felix was receiving all the care and support he needed socially, at home, at school and from the diabetes team's involvement in helping him gain the skills he needed to manage his diabetes.

The impact of diabetes on an adolescent

Despite advances in technology that ease insulin delivery with pens or pumps, Borus (2013) argued that, for an adolescent, the tasks may still be too onerous, coming at a time of social and cognitive development associated with spontaneity and increasing independence whilst still transitioning in their neurological development (Borus and Laffel, 2010; Gelder, 2013). More recently, however, Borus (2013) found that some adolescents do succeed in controlling their diabetes. Support, more than knowledge, was identified as a key factor. Indeed, Laffel et al (2003) reported that some adolescents do develop the key skills for successful diabetes management and problem-solving quickly. Perhaps, as Felix was living with little obvious support regarding his diabetes at home, this might be something for the diabetes team to build upon with Felix in a structured and supported educative way.

The physiological changes that occur during puberty are directly linked to greater insulin resistance (Amiel et al, 1986; Hanas, 2012),

which has an effect on regulating blood glucose and can challenge a child's ability to manage independently (Frederick et al, 2011). This may be one factor contributing to Felix's sub-optimal glycaemic control. In addition, the psychosocial challenges associated with hormonal changes can contribute to a time of adolescent rebellion, experimentation and risk-taking behaviours (Stewart et al, 2005). Significantly, these behaviours have been found to be higher in young people with chronic conditions (Suris et al, 2008). Young people with a lack of consistent support socially can be at increased risk, and Felix was demonstrating this in relation to his knowledge and understanding of his diabetes control.

Increased autonomy in the form of personal identity is an important developmental task of adolescence, but this process is complicated with diabetes (Newbould et al, 2008). Interestingly, Silverstein et al (2005) also identified this and argued that, although they practically have the fine motor control skills to competently perform most self-management activities, adolescents can lack the cognitive skills in problem-solving such as adjusting insulin doses, which are ever-changing for a growing teenager and affected by situations like exercise, food and stress (ISPAD, 2009). Frederick et al's (2011) study on behaviour and emotional responses to hypoglycaemia identified that decision-making requires higher-level cognitive skills than simply adhering to medical directives and highlights some of the challenges that could be affecting Felix's control as a developing teenager.

Adolescents can be less likely to use problem-solving and cognitive thinking (Wadsworth et al, 2005), and avoidance has been identified as a coping mechanism used by many teenagers. On reflection, from diagnosis both Felix and, more importantly, his mother avoided engagement with the support offered by the diabetes team, either due to feeling overwhelmed by the diagnosis or perhaps through underestimating the complexities of managing Felix's diabetes.

The impact of parental support

From a psychosocial perspective, diabetes is a significant life-event, and the initial impact can cause grief responses and crisis reactions likened to trauma (Kübler-Ross and Kessler, 2005). This cannot be underestimated for a child and family

coping with diabetes. It is difficult, at present, to ascertain if there is an element of denial both in Felix and his mother, and this needs to be explored further by the team which, in line with the BPT, includes a psychologist.

Significantly, these family dynamics and additional conflict relating to inconsistent contact with his father, who has moved away from the area, have caused Felix distress, which he has mentioned to the diabetes team. Barnard et al (2012) have highlighted that these factors place children like Felix at greater risk of psychosocial comorbidity such as depression and other emotional problems, which have been found to be alarmingly higher than in the general population. Low mood has recently been identified in Felix through not wanting to get up in the morning and poor school attendance. Dabelea et al (2014) found that low income increases the risk of admission with DKA and poor metabolic control. With regard to this finding, Felix's mother often works long hours in order to provide for her family and has, therefore, been less available to support him. Managing alone after school may have contributed to Felix's admission.

Studies have found that parental involvement is the single most important predictor of positive adolescent health outcomes (Weinger, et al, 2001; Silverstein et al, 2005; Weibe et al, 2008), at a critical time when metabolic control and adherence can deteriorate (Anderson et al, 1999). Both over- and under-involvement are associated with sub-optimal glycaemic control and altered coping in diabetes. Additionally, Wysocki (2008) argued that over-involvement by parents can feel intrusive and conflict with an adolescent's developing sense of autonomy, and has been associated with poorer diabetes outcomes (Silverstein et al, 2005).

In the context of chronic illness, research has demonstrated the role of "significant others" in supporting self-management and how social relationships shape individuals' ability to manage their care (Corbin and Strauss, 1988). Felix, however, has identified that he feels "nagged" rather than supported by his mother. Positive parenting and the sharing of responsibility for the problem-solving challenges of diabetes (e.g. making adjustments to treatment) between the parent and their adolescent child was found to contribute to self-management and promote adherence (Stewart

Page points

1. Adolescent rebellion, experimentation and risk-taking behaviours can be higher in those with chronic conditions, and young people without consistent support socially can be at increased risk.
2. Adolescents can lack the cognitive skills needed to perform effective self-management activities, such as calculating insulin dosage.
3. Family dynamics and conflict can lead to depression and other emotional problems in adolescents.
4. Both over- and under-involvement of parents are associated with sub-optimal glycaemic control in diabetes.

Page points

1. Educational attainment can suffer owing to poor concentration, low mood and poor behaviour resulting from high and low blood glucose levels.
2. As children spend a large part of their day at school, appropriate diabetes care in that setting is necessary for a child's safety, well-being and academic performance.
3. The issue of schools supporting children with medical conditions is being addressed with new legislation.

et al, 2005). Supporting the adolescent and parent in this should be an important consideration in the education process of diabetes care.

Support and the role of the school

Poor attendance of less than 50% has dominated Felix's schooling. Following diagnosis, he often missed school with complaints of headaches, abdominal pain or "high blood sugars" associated with hyperglycaemia.

Edge (2012) identified how poor concentration, low mood and poor behaviour related to high and low blood glucose levels can have an adverse effect on children's education. In addition, owing to a lack of understanding of diabetes, school staff can misinterpret these behaviours as disruptive, or accept illness and absence more readily (Edge, 2012). The level of non-attendance at school negatively affects educational outcomes (Milton et al, 2006), an important consideration for Felix.

Gaudieri et al (2008) identified that diabetes in childhood relates to slightly lower cognitive scores across most domains. Having good executive cognitive ability is, however, associated with improved control due to better problem-solving abilities, planning and organisation, and working memory (McNally et al, 2010). It was identified through the CAF assessment that Felix has dyslexia and was underachieving academically at school. Hannonen (2005) argued that dyslexia can have a negative impact on problem-solving skills and has the potential to have an effect on the ability to self-manage diabetes (Kerr and Varshneya, 2012). This needs to be considered in relation to the challenges Felix is facing with his sub-optimal diabetes management.

Children spend a large part of their waking day at school while managing the demands of their diabetes regimen (Edge, 2012). Appropriate diabetes care in the school and day-care setting is, therefore, necessary for a child's immediate safety, long-term well-being and optimal academic performance (Cox et al, 2005; DH, 2007; Gaudieri et al, 2008). Felix's school could provide considerable support as a "significant other" and provide the protective factor that he requires, if the diabetes team works with it to support his diabetes needs during school hours.

This issue is being addressed and new legislation sets out recommendations and guidance for supporting children with medical conditions at

school with an emphasis on "duty of care". In September, the DfE (2014) proposed statutory guidance that will make it a legal requirement for schools in England to support children with medical conditions, highlighting the key role that school plays as a significant other.

The hope is that these children's needs will be much more transparent, with education, health and care plans being developed for individuals whose needs are often invisible within the school setting (DH, 2007; DfE, 2014).

Conclusions

The importance of the challenges faced by an adolescent like Felix and his family cannot be underestimated. The current focus of delivering structured education in diabetes care to promote adherence to the regimen of diabetes management cannot be achieved without considering the wider complex issues related to family dynamics, and the cognitive abilities of the young person and their family. Incorporating the CAF documentation as part of a family assessment of children newly diagnosed with type 1 diabetes may provide an early alert for healthcare professionals working with children like Felix who have significant risk factors and prevent the many problems being experienced in relation to diabetes care.

With this in mind, a holistic insight into the family's health and social needs, including those of Felix's mother, will be instrumental in mobilising resources that are individually tailored to the needs of that family. This type of assessment should inform the appropriate mechanism for delivering education, as well as define the role of significant others like Felix's family and school, and drawing in external sources who can support him.

There is now a collaborative Team Around the Child and Family (TACF) in place. While challenges remain, the family are beginning to engage with the team and recognise the support that they require, and Felix is engaging with the team psychologist. Following attendance of monthly TACF meetings, Felix's HbA_{1c} has started to improve slowly. The next target in a motivational approach is to encourage Felix to improve his school attendance and to attend more diabetes team education sessions, which are provided at home, in school and in the clinic. ■

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