

Children and young people's diabetes care: Case study

Bev Day

This case study demonstrates the physical and psychological difficulties faced by many young people with type 1 diabetes. Over the year following her diagnosis, Max had a deterioration in glycaemic control despite reporting that little had changed in her management. Detailed assessment revealed a number of psychosocial factors that were preventing her from achieving good control. However, working with her multidisciplinary team, she was able to address these issues and improve her blood glucose levels. This article outlines these issues and the action plan that Max and her diabetes team drew up to overcome them.

This case study represents the challenges and issues, both physical and psychological, faced by a young person with type 1 diabetes and the support given by her diabetes multidisciplinary team (MDT). Implications for practice are addressed using current evidence-based research. The names of the child and family have been anonymised to protect their identity.

Case study

Max (a pseudonym) is a 17-year-old girl who was diagnosed with type 1 diabetes 4 years ago at the age of 13 years. She and her mother were shocked and upset by the diagnosis, and both felt its management would be too great a task to take on by themselves.

Max is an only child and lives with her mother, a single parent. She attends the local state comprehensive school and is popular with her peer group. Her mother was very involved in her care and diabetes management from the onset. Despite this, her diabetes control deteriorated over time (*Table 1*). In October 2012, her HbA_{1c} was 56 mmol/mol (7.3%); however, over the next year, this increased to 84 mmol/mol (9.8%) in July 2013. She found

it difficult to count the carbohydrate portions in her food and her injections were hurting much more than when she was first diagnosed. She also expressed a fear of hypoglycaemia and of “looking stupid” in front of her friends.

Max and her MDT discussed treatment options to improve her glycaemic control. She refused insulin pump therapy but agreed to a blood glucose monitor and bolus advisor to assist with her regimen of multiple daily insulin injections (MDI). She is now using the bolus advisor confidently and has had regular one-to-one sessions with a psychologist. She is having fewer hypoglycaemic episodes and her HbA_{1c} has improved; in January 2016 it was 69 mmol/mol (8.5%) and in April 2016 it was 58 mmol/mol (7.5%).

Discussion

Diagnosis

Max and her mother were extremely shocked and upset by the diagnosis of type 1 diabetes and the potential severity of the condition and intense management required. Both felt it would be too great a task to take on by themselves.

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Article points

1. Psychosocial factors play a large part in good glycaemic control, especially in children and young people.
2. This case study demonstrates a number of psychosocial factors that can act as a barrier to good control, and the actions taken to overcome them.
3. While there is still more work to be done, the young person described in this case study has greatly improved her glycaemic control with support from her family, friends and a multidisciplinary team working in concert.

Key words

- Adolescence
- Case study
- Glycaemic control
- Multidisciplinary team
- Type 1 diabetes

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Page points

1. A diagnosis of diabetes is a life-changing event comparable to that of loss of a loved one. Young people and their parents will often go through the five stages of grief as a coping strategy when given this news.
2. This case study highlights Max's need for support, both practical and emotional, from her multidisciplinary team, family and friends.
3. Peer support is an important aspect of diabetes management; however, friendships can sometimes have a counterproductive effect on glycaemic control and self-esteem, as young people want to feel like their peers and avoid looking different.

Table 1. Max's HbA_{1c} results over her quarterly diabetes reviews.

| Date | HbA _{1c} |
|--------------|--------------------|
| October 2012 | 56 mmol/mol (7.3%) |
| January 2013 | 64 mmol/mol (8.0%) |
| April 2013 | 73 mmol/mol (8.8%) |
| July 2013 | 84 mmol/mol (9.8%) |
| October 2013 | 81 mmol/mol (9.6%) |
| January 2014 | 70 mmol/mol (8.6%) |
| April 2014 | 60 mmol/mol (7.6%) |
| January 2016 | 69 mmol/mol (8.5%) |
| April 2016 | 58 mmol/mol (7.5%) |

Kübler-Ross and Kessler (2005) suggested that a diagnosis of diabetes is a life-changing event comparable to the experience of loss, and that children and families will often go through the five stages of grief defined by Kübler-Ross (1970) and outlined in *Box 1*. They use this as a coping strategy to enable them to eventually acknowledge the condition. However, many families never reach the fifth stage of acceptance and many will fluctuate between the stages.

Although Max and her mum did accept the diagnosis eventually, at times both of them reverted to the earlier stages of grief. The diabetes MDT supported the family from diagnosis and will continue to support them throughout their time within the paediatric diabetes service, through the transition period with both paediatric and young people's teams, until discharged to adult diabetes care.

The diabetes MDT was established after the Best Practice Tariff was introduced in 2012. It consists of doctors, nurses, dietitians, a psychologist and a personal assistant. It is well recognised that the MDT needs to work together in close cooperation to achieve good practice, and this can be strengthened by using written protocols, guidelines and targets (Brink, 2010). Logic would suggest that centres with MDTs and the same approaches and treatment regimens would have similar outcomes, yet the Hvidøre Childhood Diabetes Study Group

Box 1. The five stages of grief (Kübler-Ross, 1970).

Stage 1: **Denial** – "This can't be happening"
 Stage 2: **Anger** – "Why me?", "It's not fair", "How can this happen to me?", "Who is to blame?"
 Stage 3: **Bargaining** – "I'd do anything to turn back time", "If only I could have done things differently"
 Stage 4: **Depression** – "I'm so sad", "What's the point?", "I miss my old life"
 Stage 5: **Acceptance** – "It's going to be alright", "I can take control and manage this"

has shown this is not the case (de Beaufort et al, 2013). In terms of glycaemic control, there were notable differences in patient outcomes across 21 diabetes clinics, all of which were committed to MDT-based practice. Although factors such as age, type of insulin regimen and socioeconomic status were shown to have some influence over specific outcomes, they did not explain the apparent differences between these clinics.

Family/social history

Max is an only child and lives with her mother, a single parent. East et al (2006) suggested that rapid social change over the past 20 years has seen a marked increase in the number of mother-headed single-parent families. Max attends the local state comprehensive school, where she is generally doing well. She is popular with her peer group. La Greca et al (1995) suggested that peer relationships are important in diabetes management, as children and young people (CYP) may receive considerable emotional support from their friends. However, on occasions, Max's peer relationships have had a counterproductive effect on her, and she feels she is different from her friends as the only one who has diabetes. This at times affects her self-esteem and impacts her diabetes control.

Max's mother was very involved in her care and diabetes management from the onset. Anderson and Brackett (2005) suggested that parents typically take on most of the responsibility for management of diabetes when children are young or newly diagnosed.

Deterioration in diabetes control

Max's diabetes control had deteriorated since her diagnosis (*Table 1*). In October 2012, her HbA_{1c} was

56 mmol/mol (7.3%), which indicated a good level of diabetes control and a reduced risk of diabetes complications, as suggested by the DCCT (Diabetes Control and Complications Trial; DCCT Research Group, 1994). At her subsequent diabetes clinic appointments up to July 2013, she reported that “nothing had really changed,” except she “didn’t have time to think about her diabetes,” although she felt guilty because she knew she could make herself ill and her mum would get upset. She stated that it was hard counting the carbohydrate portions in her food and her injections were hurting much more than when she was first diagnosed. Her height and weight remained static.

Diabetes care is greatly influenced by psychosocial factors when they obstruct people’s ability to manage their diabetes and achieve good metabolic control. A team-based approach to addressing an individual’s ability to cope is critical (Kent et al, 2010). It is important for healthcare professionals to be aware of how CYP think at the different stages of their development, as their understanding of illness and chronic health conditions is often greater than that of their peers. Jean Piaget (1896–1980) investigated cognitive processes in children, calling them “schemas”. By the time children reach around 12 years of age, they can describe illness in terms of non-functioning or malfunctioning of an internal organ or process. Later in development they can appreciate that a person’s thoughts or feelings can affect the way the body functions, which demonstrates an awareness of psychological factors (Taylor et al, 1999).

Spear (2013) proposed that we can begin to understand how young people with type 1 diabetes think, feel and behave if we consider the cognitive and biological changes that occur during adolescence. Glasper and Richardson (2005) suggested there is now a growing awareness that CYP are able to make their own decisions if given information in an age-appropriate manner. Gillick competence identifies children aged under 16 years as having the capacity to consent to their own treatment if they understand the consequences (NSPCC, 2016).

Butler et al (2007) suggest that adolescence is a time of upheaval when young people have to deal with the influence of peers, school life and developing their own identity, as well as all the

physiological changes that occur. Young people with type 1 diabetes have the added responsibility of developing autonomy regarding the self-management of their condition. Hanas (2006) suggests that parents should continue to take part in their child’s diabetes care into adolescence and not hand the responsibility to the young person too early. Snoek and Skinner (2002) suggest that intensive self-management of diabetes is complex and time-consuming, and creates a significant psychosocial burden on children and their families.

There are significant challenges for CYP to engage in effective diabetes self-management. Several of these were identified with Max and her mother:

- Deterioration in diabetes control.
- Difficulty with carbohydrate counting.
- Insulin omission.
- Fear of hypoglycaemia.
- Painful injections.

Action plan

An action plan was discussed between Max and the MDT. As she was on an MDI regimen (a long-acting insulin at bedtime and rapid-acting insulin with meals), a bolus advisor/blood glucose monitor was demonstrated and discussed with her and her mum. Max felt she would be able to use this to help eliminate the calculations which, although she was capable of doing them, she often lacked time to do so. With further discussion, Max said she was “scared of getting it wrong and having a hypo”. Insulin pump therapy was discussed but she did not want to “have a device attached to my body because it would remind me all the time that I have diabetes”. Insulin pump therapy is recommended as a treatment option for adults and children over 12 years of age with type 1 diabetes whose HbA_{1c} levels remain above 69 mmol/mol (8.5%) on MDI therapy despite a high level of care (NICE, 2015a).

The National Service Framework standard 3 (Department of Health, 2001) recommends empowering people with diabetes and encourages them and their carers to gain the knowledge and skills to be partners in decision-making, and giving them more personal control over the day-to-day management of their diabetes, ensuring the best possible quality of life. However, if a diabetes management plan is discussed in partnership with

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1. Psychosocial factors have a great influence on diabetes care, and a multidisciplinary team-based approach is critical to help young people cope with a long-term condition.
2. Max had several psychosocial issues, including fear of hypoglycaemia and difficulty with carbohydrate counting, which the team were able to address.
3. Max was offered an insulin pump as a way of addressing her poor glycaemic control; however, she refused this as she did not want to always be wearing a device that would remind her she had diabetes.

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1. Max's psychological needs were assessed to identify an optimal plan of care. As a result, she attended a number of one-to-one sessions with a psychologist, dietitian and paediatric diabetes nurse.
2. She was also given a bolus calculator to help with carbohydrate counting and insulin dosing. This also helped her to overcome her fear of hypoglycaemia, which was identified as the main reason why she was sometimes omitting insulin at school.
3. To help with her painful injections, Max was switched to 4-mm needles and was taught appropriate injection technique.

a (Gillick-competent) young person but they elect not to comply with the plan despite full awareness of the implications of their actions, then the diabetes team should support them whilst trying to encourage them to maintain the treatment plan. This can be very difficult and frustrating at times, as a healthcare professional is an advocate for the patient, and promotion of the best interests of the patient is paramount.

Psychology involvement

Max was reviewed by the psychologist to assess her psychological health and wellbeing. The psychologist used the Wellbeing in Diabetes questionnaire (available from the Yorkshire and Humber Paediatric Diabetes Network) to assess her and identify an optimal plan of care.

The psychology sessions were focussed on her issues around the following:

- Fear of hypoglycaemia.
- Worry about deterioration in control.
- The consequences of insulin omission.
- Painful injections.

Max had a series of one-to-one appointments and some joint sessions with the paediatric diabetes specialist nurse and/or dietitian, so this linked into other team members' specialities.

Carbohydrate counting and use of a bolus advisor

The dietitian assessed Max and her mother's ability to carbohydrate count using a calculator, food diagrams and portion sizes, and both of them were able to demonstrate competency in this task. Garg et al (2008) have shown that the use of automated bolus advisors is safe and effective in reducing postprandial glucose excursions and improving overall glycaemic control. However, this can only be true if the bolus advisor is being used correctly and is confirmed as such by comparing blood glucose and HbA_{1c} results before and after initiation of the bolus advisor, and observing the patient using the device to ensure it is being used safely and correctly.

Barnard and Parkin (2012) propose that, as long as safety and lifestyle are taken into consideration, advanced technology will benefit CYP, as inaccurate bolus calculation can lead to persistent poor diabetes control. These tools can help with removing

the burden of such complex maths and have the potential to significantly improve glycaemic control.

Insulin omission and fear of hypoglycaemia

Max also expressed her fear of hypoglycaemia and of "looking stupid" in front of her friends. She admitted to missing some of her injections, especially at school. Wild et al (2007) suggest that a debilitating fear of hypoglycaemia can result in poor adherence to insulin regimens and subsequent poor metabolic control. Crow et al (1998) describe the deliberate omission or reduced administration of insulin, which results in hyperglycaemia and subsequent rapid reduction in body weight. Type 1 diabetes predisposes a person to a high BMI. Adolescent girls and adult women with type 1 diabetes generally have higher BMI values than their peers without the condition (Domargård et al, 1999). Affenito et al (1998) observed that insulin misuse was the most common method of weight control used by young women with type 1 diabetes. However, Max's weight remained stable and there was no clinical indication that she was missing insulin to lose weight; rather, it was her fear of hypoglycaemia that drove her to omitting insulin at school. With the use of the bolus calculator, she was reassured about her calculations for insulin-to-carbohydrate ratios, but it was reinforced with her that the device would only work efficiently if she used it correctly with each meal.

Painful injections

Max also highlighted that her injections were now more painful than when she was first diagnosed, and this was causing her distress each time she had to inject. Injection technique was discussed with her and demonstrated using an injection model, and her injection technique was observed and appeared satisfactory. She was using 5-mm insulin needles and so was switched to 4-mm needles, as recommended by Forum for Injection Technique (2015) guidelines.

Appropriate technique when giving injections is key to optimal blood glucose control; however, evidence suggests that injection technique is often imperfect. Studies by Strauss et al (2002) and Frid et al (2010) revealed disturbing practices in relation to injection technique, with little improvement over the years. Current diabetes guidelines do not include

detailed advice on injection technique, and only the guidance on type 2 diabetes in adults (NICE, 2015b) makes any reference to providing education about injectable devices for people with diabetes. However, the older Quality Standard for diabetes in adults (NICE, 2011) recommends a structured programme of education, including injection site selection and care (Diggle, 2014).

Conclusion

The issues and concerns this young girl had were identified and addressed by the diabetes MDT. She was assessed by several members of the team, and a credible, evidence-based action plan was put into place to assist her and her mother to manage her diabetes at this difficult time. Max is now using the bolus advisor confidently and having fewer hypoglycaemic episodes, and her HbA_{1c} has improved. She prefers using the 4-mm injection pen needles, although she remains hesitant when giving injections; she will still not consider insulin pump therapy. Her one-to-one sessions with the psychologist have now ceased, but she is aware she can access a psychologist at clinic on request, or if the MDT assesses that her psychological health has deteriorated.

When a child in a family develops a chronic condition such as type 1 diabetes, effective communication is vitally important to address issues with the family at the earliest stage so that problems can be discussed and, hopefully, resolved before they escalate out of control. Upon reflection, the team could have become more intensely involved at an earlier stage to prevent Max's diabetes management issues and stop her HbA_{1c} from reaching such a high level. Furthermore, the new NICE (2015a) guideline has set the target HbA_{1c} at ≤ 48 mmol/mol (6.5%), so there is still some work to be done. However, the outcome of this case appears to be favourable at present. ■

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