

Insulin manipulation and eating disorders in young people with type 1 diabetes: Implications for schools

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Article points

1. Young people with type 1 diabetes need ongoing support as they grow older and take on more elements of self-care.
2. Eating disorders in people with type 1 diabetes can manifest as insulin manipulation where doses are deliberately omitted or reduced.
3. It is extremely important to educate people with diabetes on healthy weight control practices and to make them aware of the harmful, long-term effects of insulin manipulation.
4. Research suggests that school nurse supervision of students' blood glucose monitoring and insulin self-adjustment significantly improves blood glucose control in children with poorly controlled type 1 diabetes.

Key words

- Eating disorders
- Insulin manipulation
- Type 1 diabetes
- Young people

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Young people with type 1 diabetes are at an increased risk of developing eating disorders. The coexistence of these conditions can severely compromise health and can even accelerate mortality. The use of a dangerous purging behaviour, called insulin manipulation, is of particular concern among young women with type 1 diabetes and it has been associated with metabolic dysfunction and devastating complications, such as retinopathy. Developing programmes designed to prevent individuals with type 1 diabetes developing disordered eating should be a priority, particularly for young people. This article reviews the literature surrounding type 1 diabetes and disordered eating and discusses the implications for school nurses working with young people with type 1 diabetes.

Insulin manipulation is a serious diabetes-specific weight control behaviour associated with early onset and progression of long-term complications and earlier mortality (Rodin et al, 2002). Several empirical studies have indicated that disturbed eating behaviour in people with type 1 diabetes is related to higher body mass index (Colton et al, 2001), higher weight and body shape concern, lower self-esteem, depression, feeling out of control and poor family functioning (Olmsted et al, 2008). Manipulating insulin is dangerous. It increases the possibility that the person will experience some of the medical complications of diabetes, such as vision loss, kidney failure, depression and heart damage (Neilson et al, 2002). The combination of diabetes and an eating disorder also increases the mortality rate to 35% (Nielson et al, 2002).

In America, eating disorders affect about 10% of adolescents and young adults (Ackard et al, 2008). These disorders can range from anorexia and/or bulimia to patterns of disordered eating

such as bingeing, excessive exercise or other methods of controlling calorie intake.

There is one eating disorder that is specific to people with type 1 diabetes and is more commonly seen among girls. It involves either purposefully withholding insulin or decreasing a prescribed insulin dose in order to lose weight (Rodin et al, 1991). It is known as diabulimia (Ruth-Sahd et al, 2010), but it has not been recognised as a medical condition. Adolescents often control their own insulin intake without constant supervision, so it is possible for them to limit or completely fail to take their medication without the knowledge of their parents, carers or doctors until there is evidence of significant weight loss or very high HbA_{1c} levels, indicating hyperglycaemia.

Individuals often lose weight before their diabetes is even diagnosed and insulin treatment can then lead to rapid weight gain (Starkey and Wade, 2010). Sometimes adolescents fail to take their insulin for other reasons – they may be in denial about their illness or may have a fear of

hypoglycaemia. Furthermore, they may dislike or fear glucose testing or injecting themselves, but there is also the possibility of deliberate non-compliance in order to avoid weight gain.

Individuals with type 1 diabetes may be more susceptible than the general population to developing an eating problem, since their focus may be on diet, carbohydrate intake and insulin-related weight gain, and associated body satisfaction (Striegel-Moore and Bulick, 2007). According to Colton et al (2009), featured in a review article by Young et al (2012), insulin manipulation offers individuals with type 1 diabetes a means of achieving rapid weight loss by withholding, or reducing their dose of insulin, resulting in an increased calorie loss through urination.

According to Colton et al (1999), eating disorders among adolescents with diabetes were first reported in the 1970s. The study concluded that eating disorders among people with type 1 diabetes occurred twice as often compared with adolescents without diabetes. In contrast, some researchers reporting on adolescents with type 1 diabetes challenged whether adolescent girls with diabetes are at greater risk of having eating disorders, finding few cases of such problems (Rodin et al, 1992). The authors did recommend, however, that adolescent girls and young adults with type 1 diabetes should be screened for eating disorders.

Literature review

An electronic search was performed using the databases CINAHL (Cumulative Index to Nursing and Allied Health Literature), the National Library of Medicine, PubMed, Ovid Nursing Database, ERIC (Education Resource Information Center), Medline, Health Source, Sage, ProQuest and The Cochrane Library. Dates of inclusion were 1991–2010. Peer reviewed publications that provided data on insulin withholding for weight control, caring for people with type 1 diabetes engaged in disturbed eating, school performance and school nursing were used. Commercial articles and commentary papers and abstract-only views were excluded. A total of eight articles were used for this integrated literature review.

Ruth-Sahd et al (2009; 2010) stated that restricting insulin to lose weight was widespread among women with diabetes and that many, but not most, will do this at some point. Shaw and Favazza (2010) estimated the condition was present in 14% of adolescents with type 1 diabetes and that 50% of women with diabetes had an eating disorder. Another study showed that insulin omission was a more common means of weight loss than self-induced vomiting, excessive exercise or laxative use among adolescents with type 1 diabetes diagnosed with an eating disorder (Rodin et al, 1991).

A study in 2000 compared 356 adolescent girls in Canada aged 12–19 years who had type 1 diabetes to 1098 girls without diabetes to determine the level of eating disorders in each group (Jones et al, 2000). The researchers found that about 10% of the adolescents with type 1 diabetes had an eating disorder, compared with only about 4% of the girls who did not have diabetes. They also found that about 11% of the girls with diabetes reported taking a below-normal dose of insulin in order to lose weight. As might be expected, the mean blood HbA_{1c} level was higher in the girls with diabetes who had an eating disorder than it was in the girls with diabetes who did not have an eating disorder.

Another study in 2001 looked at adolescents with diabetes and eating disorders, and sought to determine whether eating disorders were linked to poor glycaemic control (Simmons et al, 2000). The researchers studied 152 adolescents aged 11–19 years old. In general, the researchers did not find a pattern of eating disorders among adolescents with diabetes and found that some adolescents had better body satisfaction than a control group of adolescents who did not have diabetes. When they did have eating disorders they also had poor glycaemic control. The researchers also found a higher percentage (14%) of the girls with diabetes had a sub-threshold eating disorder. This is an abnormal eating pattern that meets some, but not all, of the criteria for a diagnosable disorder.

About 8% of the girls who did not have diabetes had a sub-threshold eating disorder (Simmons et al, 2000).

Page points

1. Sometimes adolescents fail to take their insulin for other reasons – they may be in denial about their illness or may have a fear of hypoglycaemia.
2. Adolescents with type 1 diabetes exhibit disordered eating by altering their insulin dosage in order to lose weight.
3. People with type 1 diabetes and an eating disorder will often have poor glycaemic control.

“Research suggests that school nurse supervision of students’ blood glucose monitoring and insulin dose adjustment can significantly improve blood glucose control in young people with poorly controlled type 1 diabetes.”

The effects of insulin manipulation and school performance

It was demonstrated by Gonder-Frederick et al (2009) that students with type 1 diabetes took a significantly longer time to complete mental maths questions and their reaction time was significantly longer when they were hypoglycaemic. During hyperglycaemia, time to complete the maths questions was significantly longer and reaction time was marginally significant. There were no differences in accuracy. Based on their findings, the decline in performance was equivalent in both hypoglycaemia and hyperglycaemia.

Health implications of insulin manipulation and eating disorders

The majority of the studies considered in the literature review stress that the use of any unhealthy weight control behaviours by people with diabetes is of serious concern. Considering the scarcity of research exploring interventions for people with type 1 diabetes engaging in disturbed eating or weight control, one approach is to incorporate cognitive behavioural therapy (CBT), a mode of treatment recommended for eating disorders (NICE, 2004).

CBT generally involves very specific goals and a structured time frame. According to Murphy et al (2010), the early sessions of CBT programme are focused on identifying the thoughts, emotions and attitudes that form the basis of the problem. With an eating disorder, these sessions seek to get the individual to recognise the irrational thoughts that motivate their disordered eating habits. This is the cognitive component of CBT. Later sessions are devoted to the implementation of specific behavioural changes that will help the individual to combat the negative and irrational thoughts. A system of goals and rewards is often used to promote positive behaviours, such as healthy eating.

Implications for school nursing practice in schools

Treatment for diabulimia in a school setting should involve a team approach, including nutritional counselling, psychotherapy to help

with body image and increase control and self-efficacy, and medical intervention from an endocrinologist. Research suggests that school nurse supervision of students’ blood glucose monitoring and insulin dose adjustment can significantly improve blood glucose control in young people with poorly controlled type 1 diabetes (Nguyen et al, 2008).

The best and safest solution is to have school staff trained to assist in routine and emergency care, under the supervision of the school nurse. Non-medical school personnel must be trained, in both routine and emergency diabetes care. It is vital that teachers can recognise signs of low and high blood glucose in their students who have diabetes.

School staff should also notify family and doctors since signs and symptoms of high blood glucose or ketoacidosis can mimic signs of flu, so it can be difficult to know whether a person has a viral infection or a more serious health problem.

The American Diabetes Association (ADA) has developed the *Safe at School Statement of Principles*, which encourages all school districts to identify individuals who will be responsible for the safe management of students with type 1 diabetes when they are in school. Ideally, those responsible persons would be school nurses trained in the management of type 1 diabetes (ADA, 2007).

As a child with diabetes becomes more independent, it seems reasonable that day-to-day management tasks will gradually be self-managed, especially during the school day; but this would not be beneficial for young people with both diabetes and an eating disorder. Young people need to feel that they are in control of their diabetes management and are following their doctor’s orders for appropriate insulin coverage; however, school nurses need to introduce self-care with supervision. Nurses need to counsel students on the importance of managing their diabetes and the roles healthy eating and exercise play in that management.

Healthcare providers must remember that interventions do not intrinsically modify behaviour but they target behavioural antecedents, which in turn have an impact

on behaviour. Interventions should avoid putting foods into categories such as good, bad, fattening, or unsafe. Nutritious foods should be encouraged for meals and snacks and the dangers of dieting should be outlined. A healthy body image should be encouraged and students should be able to talk positively about what their bodies do for them. Eating and diabetes management should be discussed in terms of health, pleasure and satisfaction, not always with regard to weight (NICE, 2004).

For a student using insulin, diabetes must be managed during the many hours spent at school, on field trips and in extra-curricular activities. In the US, the *Safe at School Statement of Principles* document is the best way to ensure that diabetes needs are met in a way that maximises safety, health, learning and participation (ADA, 2007).

Managing diabetes at school

Diabetes management is the balance between food, exercise and insulin. Effective diabetes management can allow young people full participation in all areas of the school curriculum and extra-curricular activities. The school nurse can play a key role in obtaining necessary health information, consulting with the student's physician or diabetes specialist regarding dietary recommendations and management plans, development of the individual healthcare plan, and education of school personnel who will assist with diabetes management in the nurse's absence. Personnel may include teachers and teaching assistants, physical education staff, administrative personnel and lunch staff.

Suggestions for school nurses

- Establish a daily schedule for students with type 1 diabetes – especially for observed routine blood glucose checks and insulin administration.
- Develop a way to channel information regarding student concerns between the guidance counsellor, nurse, teachers and sports teachers.
- Staff should receive training on eating disorders, or be given handouts on signs and

symptoms, including hypoglycaemia and hyperglycaemia, behavioural, emotional and physical changes to watch out for in students with type 1 diabetes.

- Be prepared to refer students/families for medical/behavioural follow-up.
- Have a checklist for the student with realistic goals and an opportunity to meet every week to go through any questions they may have about their chronic health condition.
- Students who do not eat their lunch in the lunch hall should be supervised by the nurse while eating their food.

Tips for communicating with parents or guardians

- Consider the family dynamics and any cultural or social issues that may make it difficult for the parents and families to discuss issues.
- Aim to establish and maintain a positive, open and supportive relationship with parents and families. Be mindful that parents may feel guilty, blamed, or responsible for the eating issue or disorder.

Conclusion

Society puts a lot of pressure on people to be thin. This pressure can be overwhelming for a person with type 1 diabetes. Pressure to be at a lower weight, on top of trying to achieve good blood glucose control, correct insulin dosing, healthy cholesterol numbers and blood pressure can be difficult to balance. Insulin manipulation can appear to be the answer for some people. It is extremely important to educate people with diabetes about healthy weight control practices and to make them aware of the harmful, long-term effects of insulin manipulation. Early treatment is important because the longer an eating disorder continues, the harder it is to treat (Ackard et al, 2008). Also, for young people with diabetes, the longer they do not have good metabolic control, the greater chance of long-term damage from the complications of uncontrolled blood glucose (Ackard et al, 2008).

Research suggests that school nurse supervision of students' blood glucose monitoring and insulin dose adjustment

Page points

1. Effective diabetes management can allow young people full participation in all areas of the school curriculum and extra-curricular activities.
2. The pressure to be thin can be great and insulin manipulation can appear to be an answer.
3. It is extremely important to educate people with diabetes about healthy weight control practices and to make them aware of the harmful, long-term effects of insulin manipulation.

“It is important that carers and educators remain vigilant for any signs of eating disorders or insulin manipulation.”

significantly improves blood glucose control in young people with poorly controlled type 1 diabetes (Nguyen et al, 2008). Poorly controlled diabetes and fluctuating blood glucose levels not only affect academic performance but can lead to long-term complications, such as retinopathy, cardiovascular disease and nephropathy. Maintaining blood glucose levels within a target range can prevent, reduce and reverse long-term complications of diabetes.

The ADA states that diabetes education is not a one-time event that occurs at diagnosis. At diagnosis, survival skills need to be given and then young people and their families need ongoing education and support as the child grows and gradually takes on self care. It is important that carers and educators remain vigilant for any signs of eating disorders or insulin manipulation and act swiftly to support the young person and steer them away from this destructive activity. ■

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