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PRACTICE POINTER

Managing the psychosocial impact of type 1 diabetes in young people

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What you need to know

- Adolescent and young people with type 1 diabetes (T1D) experience higher rates of psychological distress, periods of burnout, and feelings of being unable to cope with the daily burden of living with diabetes, compared with those who are diagnosed as adults
- Family, peer, and psychological support and education on living with diabetes can help to reduce distress and improve management of diabetes and wellbeing
- Consider using psychological screening assessment tools at diagnosis and annually, and developing appropriate local referral pathways to ensure adequate mental health support
- Psychological and behavioural interventions, such as solution focused therapy, coping skills training, motivational interviewing, cognitive behavioural therapy, or family centred interventions aimed at supporting the emotional wellbeing and mental health of people with T1D have shown significant improvements in quality of life and overall management of diabetes

A 19 year old patient who attends the local university recently received a diagnosis of type 1 diabetes. She requests an appointment with the GP to discuss sleep and insomnia, hoping for advice or medication to help.

On further exploration of her symptoms, it becomes apparent that she has substantial anxiety in relation to the diagnosis. She is feeling overwhelmed with the diabetes clinic appointments, frequency of blood glucose testing, insulin injections, and rumination around the potential long term complications of type 1 diabetes. The patient is living in university accommodation away from her family home and is feeling isolated. Poor sleep is one of several symptoms she describes, including loss of appetite, palpitations, and a feeling of panic. She had approached the university support services but felt they didn't fit her needs.

The incidence and prevalence of type 1 diabetes (T1D) have increased in recent decades.¹ Receiving a diagnosis of T1D is a life changing experience for the individual and their family. Learning how to live with and manage T1D is challenging at any age, but it can be particularly difficult during adolescence and early adulthood, as the constant daily management of T1D can conflict with a young person's desire to live a "normal life."^{2,3} As young people learn how to balance living with diabetes and navigating the rest of their lives, their engagement with managing their condition can diminish, especially if they do not feel supported. The burden of managing a long term condition such as T1D can cause feelings of isolation,

frustration, embarrassment, and despair. Many young people and adults feel they have to adjust their ambitions, goals, and lifestyle because of their diabetes.

How might patients present when they are having difficulties?

Disengagement and burnout

Many people experience periods of burnout in managing their diabetes, particularly during adolescence and young adulthood,⁴ During these periods they may experience increased levels of worry, feel unable to engage with diabetes management or services, or feel unable to cope with the daily burden of managing their condition. On receiving a diagnosis, adolescents and young people may experience high levels of psychological distress, and some report feeling isolated, having a sense of grieving for their former lives, or having trouble accepting the diagnosis.⁷

When faced with burnout, many young people may adopt an avoidant coping style.⁷ They may miss hospital appointments, not check their blood glucose levels regularly, or they may engage less with the daily management of their diabetes. They may report not caring about their diabetes, have frequent episodes of increased blood glucose levels, or appear disinterested in managing their diabetes or in hearing about potential complications.

Depression and anxiety

Research consistently finds that people with long term conditions such as diabetes are two to three times more likely to experience mental health problems than the general population.^{5,6,8}

When a young person presents with anxiety, low moods, or disengagement from their diabetes, social life, work, or school, consider using validated psychology screening assessment tools to ensure early referral to psychology services if appropriate.

Disordered eating and diabulimia

Levels of diagnosable eating disorders in young people with diabetes are twice as high as those in their peers without the condition.⁹ This is postulated to be because the carbohydrate counting, portion management, and dietary intake included in managing T1D present a burden that adversely affects attitudes towards food and eating behaviours.

Diabulimia, an eating disorder only seen in patients with T1D, is when patients deliberately take insufficient insulin or stop taking their insulin in order to lose weight.

Body image and issues around body dissatisfaction play a significant part in the wellbeing of young people, but notably more so in those with T1D. Behaviours that could be seen as indicators of disordered eating may include losing weight, not wanting to be weighed at the clinic, not wanting to take insulin, or not wanting to count carbohydrates or check blood glucose levels regularly.¹⁰

The prevalence and severity of psychological issues experienced can be exacerbated by the intensity of day-to-day management of diabetes, frequency and fear of hypoglycaemia, or difficulties in managing high blood glucose.¹¹ In a longitudinal 10 year study that followed 92 adolescents (aged 8-10 at diagnosis with T1D), 42% experienced at least one episode of poor mental health. The most common were disorders associated with depression, anxiety, compulsive, and/or avoidant behaviours.⁶

The UK Association of Children's Diabetes Clinicians national survey reported that access to mental healthcare and psychological support was highly variable. The report recommended that tailored diabetes education cover psychological health, peer support, and regular psychological assessment with appropriate referral pathways. The report also recommended providing mental health support to children and young people soon after diagnosis. This support should remain accessible beyond the young person's 18th birthday, and be available also to their family.¹² Many parents describe caring for a child with T1D as feeling overwhelming because of the need to be constantly vigilant, so support for parents is also imperative.¹³

What can clinicians do?

Routinely offer psychological screening at the time of diagnosis and annually thereafter. Early psychological interventions may be beneficial and have the greatest effects with young people early in diagnosis. Screening should be prioritised at times when the young person particularly needs increased psychosocial support, such as during changes in educational setting, during transition to adult services, moving away from home for the first time, when taking up a place at university, and starting employment. Examples of psychological assessment tools specific to diabetes include the Diabetes Distress scale, Problem Areas in Diabetes 20, Patient Health Questionnaire-4 (PHQ-4), and the Paediatric Quality of Life Inventory (Peds QL) 3.2 Diabetes questionnaires.^{4 5 8}

Clinicians can use psychological assessment tools to assist in detecting early psychological distress, and can ensure prompt referral to psychology services and, if necessary, intervention. Ensuring your patient knows the local referral pathways and what they might expect when they are seen within the psychological services can help them feel listened to and supported during this challenging period. Share resources with them to help them understand where they can get immediate support during any referral periods so they do not feel abandoned if there are delays.

Psychological interventions such as solution focused therapy, coping skills training, cognitive behavioural therapy, or family centred interventions aimed at supporting the emotional wellbeing and mental health of people with T1D have shown significant improvements in patients' quality of life and overall management of diabetes.¹⁴

Whether you are in primary or secondary care, ensure that psychological health is given an equal consideration to physical health in this vulnerable age group. Clinicians can help patients manage the psychosocial impact of living with T1D by taking these steps:

- Work with young people using specific and measurable goals to develop ways to manage their diabetes in a sustainable way, asking

and understanding what is important to them when prioritising their diabetes management. This might include encouraging them to break down management of their diabetes into smaller, more manageable sections—eg, just focusing on increasing the frequency of checking blood glucose levels or counting carbohydrates.

- Encourage them to engage with peer support by signposting to community groups, social media, or charities such as Diabetes UK and the Juvenile Diabetes Research Foundation. Having details of local and national peer support groups to share with patients and their families might help you start this conversation, and may encourage patients to explore these themselves. Knowing your patient's interests or hobbies might help you identify groups they relate to best.
- Identify what is important to the patient and work towards this, rather than looking purely at HbA1c levels. Support them to manage their diabetes to take part in sport, travel, or move away from home. Taking the focus away from managing their blood glucose levels may enable patients to focus on a positive goal rather than the negative elements of managing their diabetes.

Education into practice

- How often, during consultations, do you ask adolescents or young people how they are feeling or coping with their T1D? Consider times when it may be particularly important for them, such as at diagnosis or during transition periods in their life
- How would you assess whether a person with T1D is displaying signs of anxiety, depression, or disordered eating? What psychological screening tools are available? What would the referral pathway look like if a patient needed onward referral?
- How might you work collaboratively with a patient to develop priorities and goals, rather than just focusing on HbA1c? How might you focus on what is achievable, and what matters to them?

How this article was created

We conducted a systematic review using the search terms "children," "adolescents," "type 1 diabetes," "psychological," "psychology," "mental health," "well-being," "anxiety," and "depression" in PubMed, Scopus, CINAHL, Clinical Evidence, the Cochrane Collaboration, and PsycInfo from 2000 to January 2022. We reviewed the reference lists of publications.

How patients were involved in the creation of this article

ED is a patient coauthor and was involved throughout the development of this article

Contributorship and the guarantor: SMN and PK conceived the article and are guarantors. SMN wrote the initial draft. All authors wrote and reviewed the article. ED is the patient author.

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