Easing diabetes’ psychological burden

Diabetes imposes a well-recognised psychological burden, potentially leading to emotional problems, difficulties with self-management and even overt psychiatric diseases. However, Mark Greener discovers, many people with diabetes do not receive the emotional and psychological support they need.

During the 1920s, doctors realised that mental, social and familial problems contributed to fluctuating blood glucose, at least in some people with diabetes. A few people deliberately or subconsciously triggered hypoglycaemia or ketoacidosis to avoid difficult situations at home by ‘escaping’ into hospital.1

Psychological issues are not, however, isolated problems. Every person needs to adjust to the emotional, behavioural and intellectual demands of living with diabetes2 – and some succeed better than others. ‘Diabetes is inescapable, unrelenting, restricting and controlling,’ says Clare Shaban, Consultant Clinical Psychologist at Bournemouth Diabetes and Endocrine Centre, Royal Bournemouth Hospital. ‘People living with diabetes frequently describe feeling anxious, depressed, worried, afraid, guilty, blamed, angry and frustrated.’

Clare and her colleagues, for example, found increased rates of ‘clinically relevant’ anxiety in females and of depression in males with type 1 diabetes (T1D),3 which in turn can undermine self-care and worsen glycaemic control. ‘Psychological factors as well as physiological changes need to be considered to understand more fully patterns of self-care and blood glucose control,’ adds Gail Dovey-Pearce, Consultant Clinical Psychologist, Northumbria Healthcare NHS Foundation Trust and Associate Researcher at Newcastle University.

For example, addressing psychological needs improves HbA1c by 0.5–1% in adults with type 2 diabetes (T2D). Psychological interventions also reduce psychological distress and anxiety, as well as improving mood, quality of life, relationships with health professionals and significant others, and eating-related behaviours.4 Yet in a survey of 3845 people with diabetes, performed by Diabetes UK, 68% of those who needed psychological support had not received it.

**Psychological issues**

Numerous factors influence the likelihood that a person with diabetes will develop psychosocial problems, including the type of diabetes, and their coping skills, support systems and innate resilience. In people with T1D, disordered eating tends to follow diagnosis. In T2D, excessive or compulsive eating is frequently a response to emotional triggers that precede diagnosis. ‘Dietary restrictions, emotional eating and guilt associated with less “healthy” food choices are common to both T1D and T2D,’ Clare says. ‘The reduction in spontaneity associated with measuring blood glucose and carbohydrate counting is an issue more for those with T1D, while the wider change in lifestyle recommended for T2D can be a challenge for people trying to change the well-established habits of a lifetime. People with T2D report more stigmatisation, shame, blame and perceived negative judgement than those with T1D.’

**Adolescent transition and compliance**

Adolescent transition, including the move from paediatric to adult services, can be especially difficult. ‘Alongside the demands of diabetes, young people are dealing with normative developmental tasks, such as developing their sense of self and steadily acquiring autonomy. They are beginning to broaden their focus from tasks of childhood – such as friendships, academic success and community conduct – to emerging tasks of adulthood, including work, intimate relationships and future life-goals,’ Dr Dovey-Pearce says. ‘Diabetes can impact upon this developmental process.’

Young people with diabetes can feel stigmatised, fear intimacy, experience difficulties taking life decisions and face separation issues. ‘These vulnerabilities have implications in terms of a young person’s feelings about their diabetes, their engagement with health care services and their personal development,’ Dr Dovey-Pearce comments. ‘Nevertheless, effectively managing the transition, empowering patients and optimising diabetes management can engender a sense of mastery and maturity, and result in better coping skills than their well peers.’

**Understanding factors that motivate patients**

Against this background, health care professionals need to understand the factors driving behaviour. However, professionals and patients may have different agendas. Patients often prioritise immediate quality of life. Health care professionals are continually cognisant of tight glycaemic control to reduce the risk of complications.2

‘Health care professionals need to understand why some people find managing diabetes difficult. It is necessary to unpick the thoughts and feelings that influence behaviour and motivation,’ Clare suggests. ‘It is important to appreciate the barriers as well as the person’s knowledge, skills, social and family support. Above all, it is essential to be empathic and non-judgemental.’

Clare suggests that asking three questions can help assess the distress associated with diabetes. (See Box 1.)

Other questions that help understand the patient’s perspective include:2

- What does it mean to you to live with diabetes?
- Does how you feel in yourself influence how you manage your diabetes?
- Is there anything else happening in your life at present that seems more important than your diabetes?

**Box 1. Three questions which can help assess the distress associated with diabetes**

- What does it mean to you to live with diabetes?
- Does how you feel in yourself influence how you manage your diabetes?
- Is there anything else happening in your life at present that seems more important than your diabetes?
‘Such questioning can help elucidate common precipitants of negative thoughts and feelings, such as insensitivity from other people, intrusive well-intentioned but unhelpful advice, and fear of hypoglycaemia and long-term health issues,’ Clare explains.

‘A psychologist will work to identify all likely factors contributing to current distress, within the comprehensive psychological assessment. Setting collaborative goals with the patient will focus the therapeutic work on the most salient issues at that time,’ Dr Dovey-Pearce notes.

**What is called for**

‘There is very limited or no specialist psychological support and treatment for people with diabetes,’ Clare says. ‘This is one factor inhibiting improved psychological care: health care professionals worry about “opening a can of worms”. Many do not have any basic training in psychological skills and refer people repeatedly for educational support.’ Yet, in 2012–13, only 1.1% of people with T1D and 1.6% of those with T2D attended a structured education; among people with newly-diagnosed diabetes, only 0.9% and 3.6% of those with T1D and T2D respectively attended.

Bournemouth Diabetes and Endocrine Centre was one of the first departments in the UK to include a clinical psychologist, with psychology integrated into all care pathways. In contrast, many people with diabetes in other parts of the country are signposted to mental health services, usually Improving Access to Psychological Therapies (IAPT). ‘This creates an artificial divide between physical and mental health that rarely meets the needs of the patients,’ Clare notes. ‘IAPT for generic long-term conditions isn’t good enough – we need psychologists and counsellors with specialist diabetes knowledge.’

**Best Practice Tariff**

Psychological care is now included in the Best Practice Tariff (BPT) for children. ‘Recognition of the role of psychology in diabetes was central in the diabetes National Service Frameworks,’ Dr Dovey-Pearce says. ‘The BPT has helped resource psychology in paediatric diabetes. This has been about a move from guidance towards requirement.’

However, the BPT doesn’t cover support for adults, where access to psychological services remains poor. ‘NHS trusts fear the cost of providing for psychological needs. However, they can’t afford to continue to fail to provide this support,’ Clare says. ‘NICE guidelines, national policy documents and Quality Standards, for example, all include recommendations for psychological support and treatment – but they are largely disregarded. Commissioners need to implement these without cherry picking the recommendations.

‘Many problems faced by people with diabetes are complex and interconnected. Often, these require treatment from a specialist diabetes psychological therapist,’ Clare remarks. ‘However, commissioners and other people making decisions about funding frequently do not understand what it means to live with diabetes, they do not understand psychology or the interconnections. It is not enough to tell people with diabetes what to do.’

Clare also underscores the importance of appropriate psychological training for the entire diabetes team. ‘The psychological aspects need to be integral to the training of all members of diabetes teams. The training needs to include not only psychiatric comorbidities, especially depression, but also the psychological themes that contribute to diabetes distress, including guilt, shame, blame, control, stigma and behavioural mismanagement.’

Against this background, Clare notes that Diabetes UK’s State of the Nation report 2015 gives clear direction to CCGs to ‘commission specialists in psychological care and diabetes, and ensure these form part of multidisciplinary diabetes teams and paediatric diabetes services’. The report also calls for CCGs to work together with providers to ‘design and implement integrated diabetes services... which cover the full spectrum of mental and physical health care’.

**Evidence that psychological services work**

Ironically, given the reluctance to invest, improved psychological services save money. The NHS Confederation, for example, modelled costs associated with investing in six months of collaborative care in England for 119 150 patients with newly-diagnosed T2D who screen positive for depression, compared with usual care.

Completing and successfully responding to collaborative care delivered in primary care leads to an additional 117 850 and 111 860 depression-free days in years one and two respectively. The cost in the first year was £7 298 860 in health and social care, partly offset by a reduction of £331 170 in productivity losses. In year two, the savings reached £385 240 and £314 330 respectively – a net saving of £699 570. The cost per quality adjusted life year gained was £5614, suggesting the approach is highly cost effective.

However, these findings do not capture the full benefits offered by enhanced psychological support, including savings associated with fewer complications. ‘Services should be evaluated using psychology outcome measures such as diabetes-specific distress, quality of life, mood, body image, eating behaviours and attitudes – and biomedical outcomes, including blood glucose levels and body mass index,’ Clare remarks. ‘Services should consider monitoring other factors such as patient satisfaction, and the skills and confidence of the multidisciplinary team in managing psychological issues.’

**A role at all stages**

Diabetes affects the mind and the mind affects diabetes. So, psychologists who are unable to draw on adequate resources, staff with poor psychological skills and nihilism among commissioners, despite a robust evidence base, probably play a large role in the systemic failure. ‘Joint care planning and case working, with a psychologist embedded as part of the multidisciplinary team, would be the ideal way to meet individual needs in an effective way,’ Dr Dovey-Pearce comments. As Clare concludes, ‘Psychology is not a last resort, it has a role at all stages of care.’

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**References**

References are available in Practical Diabetes online at www.practicaldiabetes.com.
References