Understanding the psychological impact of diabetes and the role of clinical psychology

Online learning opportunity

See page 142 for details.

Jen Nash

Diabetes is a life-long condition requiring complex self-management and medical treatment. A diagnosis of diabetes will have a significant impact on an individual's life, and regular medication, frequent appointments and lifestyle changes can lead to a number of emotional responses, including depression and anxiety, eating disorders and problems with personal and sexual relationships. This article describes the symptoms and signs associated with these issues and outlines the role of clinical psychology in combating them. Ten multiple-choice questions are included at the end of the article to test your knowledge.

Diabetes has been likened to a job – and not just any job – one in which the person with diabetes has to work 24 hours a day, 7 days a week, 365 days a year, with no holiday, no praise and no pay. This is challenging enough; add into the mix low mood, eating issues, or sexual problems and we can see why HbA_{1c} may be as affected by emotions as by medication. This article aims to outline the psychological issues that may affect the person with diabetes in order to equip clinicians with a heightened awareness of detecting these and referring on for appropriate support.

Dealing with diagnosis

The diagnosis of diabetes is a life event that has been likened to the experience of grief (Kubler-Ross and Kessler, 2005). In the same way as it is natural to grieve for a lost loved one, the diagnosis of diabetes can trigger a grieving for one's "lost health". It is, to some extent, part of the human condition to live life as if we are invincible, rarely considering our health or mortality; however, this dramatically changes when diagnosed with a chronic health condition as the person can become suddenly acutely aware that their life is not without limits. They now have to rely on regular medication, changes to their lifestyle, frequent visits to a medical setting and a team of doctors and nurses to keep themselves well. *Box 1* outlines the stages of grief, first described by Kubler-Ross (1997). Not everyone with diabetes will necessarily experience all of these emotional reactions, or in this particular order. Just as the process of grief can be one that lasts for a long time, many people struggling with the diagnosis of diabetes can oscillate back and forth between a number

Box 1. The stages of grief (Kubler-Ross, 1997).

- 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 OK", "I can take control and manage this".

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Article points

1. A diagnosis of diabetes can have a significant impact on an individual's life; they have to rely on regular medication, changes to their lifestyle, frequent visits to a medical setting and a team of doctors and nurses to keep themselves well.
2. Diabetes can, therefore, lead to a number of emotional problems, including depression, anxiety, eating disorders and problems with personal relationships.
3. This article highlights some of the signs and symptoms of these developing issues and discusses the important role of the psychologist.

Key words

- Anxiety
- Depression
- Diabetes
- Psychology

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1. Working with a psychologist can help the individual acknowledge the often unvoiced feelings they are carrying about their diabetes.
2. People with diabetes are 2–3 times more likely to be considered depressed than those without diabetes. The burden of diabetes care, with its necessary lifestyle changes and self-management tasks, can detrimentally affect quality of life.
3. People with diabetes are more likely to feel anxious and fearful. Diabetes can bring with it two specific forms of anxiety: fear of hypoglycaemia and fear of needles.

of these stages for many years, getting stuck at denial, or between anger, bargaining and depression, perhaps with small acceptances along the way. Others may never truly accept their condition. Working with a psychologist can help the individual acknowledge the often unvoiced feelings they are carrying about their diabetes – often years after their actual diagnosis – in order to integrate the diagnosis into their identity and allow a more congruent relationship to develop.

Depression, low mood and burnout

Research has demonstrated that low mood and depression are very prevalent among people with diabetes. The individual with diabetes is 2–3 times more likely to be considered depressed than the person without diabetes (Barnard et al, 2006). The burden of diabetes care, with its necessary lifestyle changes and unremitting self-management tasks, can detrimentally affect the quality of life of the person with diabetes (Rubin, 2000). The World Health Organization (2014) defines depression as:

> *"...depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration."*

There are also a significant number of individuals who do not report symptoms of depression, but still feel low in relation to their diabetes. These individuals may be struggling with diabetes-specific distress, coined "diabetes burnout" (Polonsky, 1999). Diabetes burnout occurs when a person feels overwhelmed by diabetes and the frustrating burden of diabetes self-care. These emotions may be very different to feelings of depression, although they can still be very destructive and have serious implications for care. Barnard and Lloyd (2012) describe burnout as:

- Feeling overwhelmed and defeated by diabetes.
- Feeling angry about diabetes, frustrated by the self-care regimen and/or having strong negative feelings about diabetes.
- Feeling that diabetes is controlling their life.
- Worrying about not taking care of diabetes well enough, yet unable, unmotivated or unwilling to change.
- Avoiding any diabetes-related tasks that might give feedback about consequences of poor control.
- Feeling alone and isolated with diabetes.

Diabetes burnout centres on feelings focused specifically about diabetes, while depression affects the person in more broad psychological ways in which the person has negative thoughts about the self, the world and a hopelessness for the future.

Answering the following two screening questions every day may indicate the presence of depression (Kronke et al, 2003):

- Over the last 2 weeks, how often have you been bothered by any of the following problems?
  - Little interest or pleasure in doing things.
  - Feeling down, depressed, or hopeless.

With appropriate psychological support, depression and diabetes-related burnout are treatable and many people go on to make a full recovery. Psychological therapy can help the individual to address issues, both in the present and from the past, that may be affecting their thinking styles and sense of identity, both in relation to their diabetes and in their life more broadly.

Fear and anxiety

Anxiety is a natural human response that has evolved as a reaction to situations that we perceive as dangerous. In our evolutionary history, our ancestors needed fast and effective responses to survive living in a hostile world, in which predators were many and often unpredictable. Diabetes can bring with it two specific forms of anxiety: fear of hypoglycaemia and fear of needles (Hamilton, 1995).

Fear of hypoglycaemia

The effects of a hypoglycaemic episode can be frightening, embarrassing, uncomfortable, unpleasant and, in the worst case, fatal. For some individuals, having just one aversive or frightening episode of hypoglycaemia can lead to increased anxiety of it happening again (Polonsky, 1999). This can lead to other

behaviours, which in turn, may lead to further difficulties with managing diabetes:

- Running blood glucose levels higher than usual to avoid hypoglycaemia.
- Eating more than is needed in an attempt to keep blood glucose level elevated.
- Restricting activities where a hypoglycaemic episode would be more challenging to deal with, such as driving, exercising and travelling on public transport.

Fear of needles

For many people with diabetes, injections and blood glucose testing are simply a necessary part of life. Yet for others, both newly diagnosed and those who have been managing the condition for longer, the injection and blood glucose testing process can be very distressing. The main feature of needle phobia is anxiety at the thought of injections or blood glucose testing, leading to attempts to avoid them. This may be associated with feeling dizzy and light-headed, a dry mouth, palpitations, sweating, trembling, over-breathing, feeling sick and even fainting (Jenkins, 2014). Psychological interventions can assist the person with diabetes to develop a "fear hierarchy", which supports them to progressively confront their fears, accompanied by thought challenging and relaxation strategies (Fernandes, 2003).

Eating issues

For many people, both with and without diabetes, food can offer more than just fuel for the body. The connection between food and emotion is one that is established from birth. From a very young age, food is intimately linked with emotions – our caregivers soothed us with milk when hungry and crying (Carnell et al, 2012). Everyone, of every shape and size, can use food to deal with their emotions, and occasionally it can be fine to use food in this way. It is not a problem for the individual who has a wide repertoire of ways to soothe their emotions when needed. The difficulty is when food becomes the only way to deal with emotions. Many people go their whole lifetime using food in this way and often it does not cause much harm; however, once diagnosed with diabetes, the person needs to be much more mindful of the role food plays in their life (Pozzilli and Fallucca, 2014).

When using food to regulate emotions, the drawback is that the original stressor still remains and using food in this way can add the associated problem of guilt and remorse for the overeating. With two problems to now deal with, and the self-criticism that can come with emotional eating, the original problem is magnified, not solved.

Many people know what they should be doing, but cannot

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1. A diabetes-specific eating disorder is insulin omission, often referred to as "diabulimia". With insulin omission, whether by decreasing, delaying, or completely omitting prescribed insulin doses, a person with diabetes can induce hyperglycaemia and rapidly lose calories in the urine in the form of glucose.
2. People with diabetes may feel anxious about attending medical appointments and it can be common for many people to either avoid going to their appointments completely or to feel a range of difficult emotions when they do go.
3. Excellent strides are now being made to empower people with diabetes to self-manage their condition more effectively through structured education programmes such as DAFNE (Dose Adjustment For Normal Eating) and DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed).

follow the seemingly simple advice to "eat less and move more" given by their healthcare professionals, who may also be at a loss to know how to help. The psychologist can assist the person reach a place in which they can make a decision about whether or not to eat when they are feeling emotional – rather than it just being an automatic response.

Insulin omission

Eating behaviour is rarely straightforward. An eating disorder is diagnosed if the person's attitude towards food causes them to change their eating habits and behaviours in a way that may cause damage to their health.

A diabetes-specific eating disorder is insulin omission, often referred to as "diabulimia". With insulin omission, whether by decreasing, delaying, or completely omitting prescribed insulin doses, a person with diabetes can induce hyperglycaemia and rapidly lose calories in the urine in the form of glucose (Criego et al, 2009). Insulin manipulation can be carried out in quite a secretive way, so it often goes undetected by healthcare professionals.

Unfortunately, insulin omission can also be easily misunderstood and labelled as the individual being "non-compliant" with treatment. However, individuals who are manipulating their insulin are struggling with an eating disorder.

Signs that may indicate insulin omission have been outlined by Criego et al (2009):

- Overall deterioration in psychosocial functioning, including school attendance and performance, work functioning, and interpersonal relationships.
- Recurrent/frequent ketoacidosis.
- Increasing neglect of diabetes management, including blood glucose monitoring, insulin titration (insulin omission), and adherence to other medications.
- Purging behaviours, such as excessive exercise, laxative/diuretic use or vomiting.
- Erratic clinic attendance.
- Poor body image/low self-esteem.
- Significant weight gain or loss.
- Frequent dieting and increased concern about meal planning and food composition.
- Bingeing.

A therapeutic relationship can help the individual to understand what is at the root cause of their difficulties relating to food, and increase their self-esteem and ability to feel in control of their life.

Communicating with health professionals

Developing a good working relationship with the healthcare team can go a long way towards feeling supported in the diabetes journey. However, the medical model with its inherent "expert and patient" dynamics can invite both conscious and unconscious associations with other authority contexts, such as school and parental figures. Attachment theory proposes that individuals internalise early experiences with parental caregivers and form an internal model that determines their view of themselves and others, and whether they are worthy of care (Ciechanowski et al, 2001). Whether or not the individual is aware of this, it can be common for many people to either avoid going to their appointments completely or to feel a range of difficult emotions when they do go.

Excellent strides are now being made to empower people with diabetes to self-manage their condition more effectively through structured education programmes such as DAFNE (Dose Adjustment For Normal Eating) and DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) and outcomes that for many people have been demonstrated to be sustained over time (Speight et al, 2007). These courses are patient-centred and place an emphasis on people with diabetes themselves becoming experts in their disease management. However, not all individuals with diabetes who are offered a place on a structured education programme attend, and the reasons for this are likely to be multifaceted, for example, not understanding its importance; language/cultural barriers; competing priorities; time demands and not feeling comfortable in a group setting. The psychologist can provide a "safe space" to name, normalise and explore some of these issues and create a dialogue for the individual to feel secure in their relationships with their team.

Family relationships

Diabetes does not just affect the person living with the condition – it has the potential to affect the whole family system too (Holt and Kalra, 2013). Family members can express their concern and worry in a multitude of different ways. Some loved ones may have a tendency to be over-involved with the management of diabetes, which can feel suffocating to the person with the condition. The opposite situation can also happen, in which family members withdraw and seemingly ignore the changes, leaving the person with diabetes feeling lonely and isolated. Working with a psychologist, either individually or with the family members, can empower the individual to communicate what they need from their family in a way that allows them to have their voice heard.

Sexual difficulties

Difficulties with sexual response can be a very common experience for people with diabetes and can affect males and females in different ways (Maiorino and Bellastella, 2014). For the person with diabetes this can be a further setback – not only do they need to deal with the challenges of managing diabetes, now the part of their identity that could be expressed through their sexual relationship is affected.

Psychological approaches can normalise these issues, and assist the person with a programme of "sensate focus", addressing the cognitive and behavioural aspects of their sexual relationships.

Summary

Psychological factors can complicate the management of diabetes, yet most people with diabetes do not have access to a psychologist (Diabetes UK, 2008). The recommendation for psychological support and treatment for people with diabetes has been made repeatedly in NICE guidelines and quality standards (NICE, 2011), in national policy documents, and by Diabetes UK. In most cases some of the complex psychological problems that diabetes can cause can be lessened with the help of a clinical psychologist. A shift in the NHS culture and commissioning climate to allow recognition of psychological services is needed and services, such as "3 Dimensions for Diabetes" at King's College Hospital (Archer et al, 2012) have demonstrated that social and psychological support can not only improve well-being but also decrease HbA_{1c} by an average of 10 mmol/mol (0.9%). ■

"Psychological factors can complicate the management of diabetes, yet most people with diabetes do not have access to a psychologist."

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Online CPD activity

Visit www.diabetesonthenet.com/cpd to record your answers and gain a certificate of participation

Participants should read the preceding article before answering the multiple choice questions below. There is ONE correct answer to each question. After submitting your answers online, you will be immediately notified of your score. A pass mark of 70% is required to obtain a certificate of successful participation; however, it is possible to take the test a maximum of three times. A short explanation of the correct answer is provided.

Before accessing your certificate, you will be given the opportunity to evaluate the activity and reflect on the module, stating how you will use what you have learnt in practice. The CPD centre keeps a record of your CPD activities and provides the option to add items to an action plan, which will help you to collate evidence for your annual appraisal.

1. Which of the following is not a stage of grief associated with diagnosis of diabetes? Select ONE option only.

A. Denial.
B. Guilt.
C. Depression.
D. Acceptance.

2. People with diabetes are how many times more likely to be considered depressed than those without diabetes? Select ONE option only.

A. None at all.
B. 1–2 times.
C. 2–3 times.
D. 3–4 times.

3. Depression in diabetes is different from diabetes burnout because: Select ONE option only.

A. Diabetes burnout centres on feelings focused specifically about diabetes.
B. Diabetes burnout causes the person to have negative thoughts about themselves, the world and a hopelessness for the future.
C. They are the same condition.
D. Diabetes burnout can not be treated with psychological therapy.

4. Which of the following TWO statements are included in the depression screening questions?

A. Little interest or pleasure in doing things.
B. Crying a lot more than usual.
C. Feeling down, depressed, or hopeless.
D. Not leaving the house.

5. Which of the following statements about diabetes-related fears is incorrect? Select ONE option only.

A. They can cause high HbA_{1c}.
B. They are often not admitted to the healthcare team.
C. They can cause embarrassment.
D. They are untreatable.

6. Which of the following statements about sexual problems in people with diabetes is correct? Select ONE option only.

A. They occur more frequently in people with diabetes than people without.
B. They are a lifestyle issue and not relevant in the medical setting.
C. They are just biological.
D. They cannot be treated.

7. Why do some people with diabetes struggle to follow the "eat less, move more" advice? Select ONE option only.

A. They may be using food to regulate their emotions.
B. The health setting may not be conducive to talking about emotional eating.
C. The individual may not be aware of times when they eat for non-hunger reasons.
D. All of the above.

8. Which of the following statements about insulin manipulation is correct? Select ONE option only.

A. Insulin manipulation does not exist.
B. It is an eating disorder.
C. It is just a phase; you can grow out of it.
D. It is a sign that the individual is being manipulative.

9. Which of the following are signs that may indicate an eating disorder? Select ONE option only

A. Significant weight gain or loss.
B. Poor body image/low self-esteem.
C. Recurrent/frequent ketoacidosis.
D. All of the above.

10. Which of the following statements about communication is correct? Select ONE option only.

"Developing a good working relationship between the person with diabetes and the healthcare professional is":

A. Only impacted by the empathy of the healthcare professional.
B. Only impacted by the attachment style of the person with diabetes.
C. A dynamic relationship between professional and patient.
D. Irrelevant to the management of diabetes.