Supporting the emotional well-being of patients with diabetes mellitus in primary care

Charlotte Gordon

Abstract
Diabetes mellitus is a condition characterised by elevated blood glucose levels that can lead to significant acute and long-term complications. Alongside these physical complications, the condition can have substantial effects on people’s emotional well-being, potentially resulting in diabetes distress and/or major depressive disorder. Therefore, timely assessment and referral of patients with diabetes who display signs and symptoms of diabetes distress or other mental health conditions are essential. This article discusses emotional well-being in patients with diabetes, and outlines some diabetes-specific validated assessment tools that can be used in practice. It also discusses the management and appropriate onward referral of people with diabetes who require support.

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Living with diabetes mellitus not only affects people’s overall physical health but can also have a significant effect on their emotional well-being. Knowledge of the complexity of diabetes can enable nurses to understand the emotional burden of the condition. Early assessment of emotional well-being, providing advice and making appropriate onward referrals are central to improving the well-being of people with diabetes and limiting long-term complications.

This article focuses on the burden of living with diabetes and its effects on people’s emotional well-being. It suggests approaches to patient assessment using relevant tools and strategies for person-centred care and management.

Diabetes mellitus
Diabetes is a common long-term condition. In the UK, its incidence has more than doubled in the past 15 years, with around 4.9 million people (1 in 14) living with the condition – a figure predicted to rise to more than 5.5 million by 2030 (Diabetes UK 2021a).

Diabetes is characterised by chronically elevated blood glucose levels (hyperglycaemia) arising from relative or absolute deficiency of the hormone insulin produced by the pancreas. Insulin regulates blood glucose levels by facilitating the uptake of glucose by the cells, where it can be used for energy. The main types of diabetes are type 1 and type 2, with rare subtypes such as gestational diabetes, latent autoimmune diabetes and diabetes arising from single gene mutations (monogenetic diabetes) (World Health Organization (WHO) 2019). Around 90% of people with diabetes have type 2, 8% have type 1 and the remaining 2% have rare forms of the condition (Smyth 2020).

Diabetes management is complex and requires lifestyle modifications in terms of diet and physical activity (Khaltaev and Axelrod 2021). Daily oral medicines and/or insulin injections, alongside close monitoring of blood glucose levels, may also be required. Such self-management is crucial to reduce the risk of serious long-term complications, such as cardiovascular disease, amputation, renal failure,
neurological impairment and vision loss (Papatheodorou et al 2015). This places constant, daily demands on individuals, potentially leading to reduced quality of life (Smyth 2020, National Institute for Health and Care Excellence (NICE) 2022). Effective self-management requires constant motivation and changes in behaviour, so the effect of diabetes on people’s psychological and emotional well-being can be profound (Diabetes UK 2021b). Indeed, some people perceive their life as having been ‘invaded’ by diabetes (Kneck et al 2012).

Diabetes and emotional well-being
Living with diabetes places a significant burden on people due to the physical and psychological complications associated with the condition. People with long-term conditions experience further physical complications if they also develop mental health issues (NHS England 2016). Compared with the general population, people with diabetes are twice as likely to experience depression, and are more likely to be depressed more frequently and for longer, while around 40% of them have diminished psychological well-being due to the constant demands of the condition (Whicher et al 2020).

A literature review by Kalra et al (2018) explored the emotional and psychological needs of people with diabetes, identifying that psychological factors can increase the risk of diabetes-related complications and mortality. These authors also discussed the complex association between diabetes and mental health conditions, describing the multiple effects that they can have on each other, either arising concurrently or contributing to the pathogenesis of each other. Additionally, Kalra et al (2018) suggested that mental health conditions are a risk factor for the development of diabetes.

Diabetes UK (2017a) includes emotional and psychological support as one of its 15 Healthcare Essentials, which detail the checks, tests and services people with diabetes are entitled to receive. It also emphasises the importance of discussing patients’ concerns about their well-being.

Challenges of meeting patients’ emotional well-being needs
According to Jones et al (2014), person-centred care – which includes addressing psychological needs – is often not available to many people with diabetes. Most diabetes management takes place in primary care, with an estimated 20 million diabetes contacts annually, and nurses have a significant role in the ongoing review and management of patients with the condition (Dambha-Miller et al 2020). However, it is notable that emotional and psychological support is not a quality outcome framework indicator for diabetes care (NHS England 2020) nor one of the annual care processes included in the National Diabetes Audit (NHS Digital 2018, 2021), which are focused on physiological complications. Therefore, there is incongruence between the demonstrable effects of diabetes on people’s well-being and the metrics from which health indicators and measurements are derived in primary care.

In addition, the NICE (2021) guideline on the diagnosis and management of adults with type 1 diabetes outlines the need to identify the development or presence of clinical or subclinical depression and/or anxiety, particularly in relation to the burden of self-management, yet the revised NICE (2022) guideline on the management of adults with type 2 diabetes makes no such reference to well-being. This suggests a disparity between the importance placed on the well-being of people with different types of diabetes, when the effect of the condition on people’s well-being is ultimately the same. In contrast, Ali et al (2021) identified the restructuring of clinical commissioning groups as primary care networks as an opportunity to strengthen joined-up specialist care to address the holistic needs of people with diabetes, and recommended an integrated approach to physical and mental health across primary care networks.

Dambha-Miller et al (2020) found there was a reluctant consensus among patients, GPs and nurses that in primary care only minimum standards in the care of people with type 2 diabetes can be achieved, and that aspirations for high-quality care provision are unlikely to be met. Similarly, Rushforth et al’s (2016) systematic review of the barriers to effective management of type 2 diabetes in primary care reported that limited time, resources and lack of confidence in knowledge of guidelines and skills make it challenging for primary care professionals to meet treatment targets. This can lead to frustration about the subsequent compromises in diabetes management, as well as confusion about roles and responsibilities due to the multidimensional nature of diabetes care (Rushforth et al 2016).

Maxwell et al (2013) undertook a qualitative study of primary care professionals’ views of case finding for depression in patients with diabetes or coronary heart disease. In this study, nurses described experiencing difficulty with incorporating assessments into routine reviews and replacing individualised care with mechanistic assessments, as well as a disconnect between physical and mental health and uncertainty about referral or care provision. Furthermore, Diabetes UK (2019a) surveyed 1,000 GPs in the UK, finding that only 30% believed there was sufficient emotional and psychological support for patients with diabetes.

Well-being may often be missed as a central component of care for several reasons, including the workload pressure of nurses in primary care – magnified during the coronavirus disease 2019 (COVID-19) pandemic – as well as the focus on physiological measures of effective diabetes management and a lack of knowledge about the condition. However, it is important to recognise that for people with diabetes, issues related to well-being are often more tangible and meaningful than improvements in blood glucose levels (Jones et al 2014).

Diabetes distress and major depressive disorder
People with all types of diabetes commonly experience psychological distress (Jones et al 2014). Well-
being in relation to diabetes may be considered a continuum from healthy coping, through to diabetes distress, then to mental health conditions such as major depressive disorder (NHS Diabetes and Diabetes UK 2010). Early screening, prevention and treatment of diabetes distress and/or depression can result in improvements in diabetes self-management and quality of life for people with type 2 diabetes (Owens-Gary et al 2019).

Diabetes distress is a recognised emotional state in which an individual experiences guilt, fear, stress and denial arising from the burden of living with and managing their condition and its social effects (Young-Hyman et al 2016, Hardy 2021). It has been estimated that diabetes distress affects 36-45% of people with type 2 diabetes and it is particularly prevalent among women and those with comorbid depressive symptoms (Kreider 2017, Perrin et al 2017). Increasing diabetes distress is correlated with elevated blood glucose levels and decreased efficacy of self-management, impaired quality of life and more frequent, severe episodes of hypoglycaemia (Hendrieckx et al 2019).

Diabetes and major depressive disorder frequently coexist and may be bidirectional (Kreider 2017). People with an early diagnosis of diabetes, a high body mass index, suboptimal glycaemic control, diabetes complications and lower levels of education are at increased risk of developing significant depressive symptoms (Hermans et al 2013). Major depressive disorder also has an inverse relationship with optimal diabetes outcomes (Kreider 2017).

While diabetes distress and major depressive disorder are closely associated and there is significant overlap between them (Perrin et al 2017), they are separate conditions (Gonzalez et al 2008). The patient’s presenting symptoms may enable healthcare professionals to differentiate between the two conditions and support appropriate assessment and management. Box 1 lists the main symptoms of diabetes distress and major depressive disorder.

### Using the 7 As model to assess and manage well-being

The 7 As model (Figure 1) (Hendrieckx et al 2019) is a seven-step process that nurses can use in their clinical practice. The model has clinical utility and provides a memorable, consistent and logical pathway for screening and monitoring of issues related to emotional health as part of a person-centred approach to care (Halliday et al 2020). The model provides prompts to assist healthcare professionals in identifying diabetes distress (aware, ask, assess) and in initiating support (advise, assist, assign, arrange) (Hendrieckx et al 2019). It can also provide a summary of issues related to a patient’s well-being.

**Aware, ask and assess**

Diabetes UK (2019b) has provided guidance on how to have a ‘quality conversation’ about patients’ well-being. In any nursing consultation, it is essential to use appropriate language because this can develop patients’ confidence, reduce their anxiety and enhance their self-management, whereas suboptimal communication can be harmful, stigmatising and detrimental to clinical outcomes (NHS England 2018).

Quality conversations with patients could be structured as follows (NHS England 2018, Diabetes UK 2019b):

- **Step 1 – opening up** a conversation, for example by asking ‘How are you feeling?’
- **Step 2 – making the most of the conversation**, for example gaining insight by asking the patient to complete a validated self-assessment before an appointment and using the responses during the appointment as a prompt for exploring the issues raised. This step may also involve open questioning, active listening, reflection and the use of positive verbal and non-verbal language which reflects that used by the patient.
- **Step 3 – safely closing a conversation**, for example by agreeing actions, asking the patient to summarise the discussion and if they have any questions, and ending on a positive note that

### Key points

- The self-management of diabetes mellitus is crucial to reduce the risk of potentially fatal long-term complications, but places constant, daily demands on individuals, potentially leading to reduced quality of life.
- Well-being in relation to diabetes may be considered a continuum from healthy coping, through to diabetes distress, then to mental health conditions such as major depressive disorder.
- Assessment tools can support nurses to explore diabetes-specific effects on patients’ well-being, identify issues of particular importance, and inform referral to specialist mental health support when required.
- Nurses should act within the limits of their knowledge and skills and make onward referrals as appropriate, while ensuring continued contact with patients to provide consistency and effective long-term monitoring and care.

emphasises the importance of well-being. Another appointment should be arranged or the patient should be referred to a specific service or organisation as necessary.

### Box 1. Main symptoms of diabetes distress and major depressive disorder

<table>
<thead>
<tr>
<th>Symptoms of diabetes distress</th>
<th>Symptoms of major depressive disorder</th>
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<tbody>
<tr>
<td>Lack of motivation</td>
<td>Anhedonia (inability to feel pleasure in normally pleasurable activities) or depressed mood</td>
</tr>
<tr>
<td>Burn out</td>
<td>Diminished interest or pleasure in daily activities</td>
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<tr>
<td>Feeling overwhelmed</td>
<td>Changes in appetite (weight gain or loss)</td>
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<tr>
<td>Frustration</td>
<td>Insomnia or hypersomnia</td>
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<tr>
<td>Feeling defeated</td>
<td>Psychomotor agitation or retardation</td>
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<tr>
<td>Anger</td>
<td>Fatigue</td>
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<tr>
<td>Guilt</td>
<td>Feelings of worthlessness or guilt</td>
</tr>
<tr>
<td>Loneliness</td>
<td>Diminished concentration</td>
</tr>
<tr>
<td>Suboptimal self-care behaviours</td>
<td>(Kreider 2017)</td>
</tr>
<tr>
<td>Lack of concordance with diabetes management</td>
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</table>

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One challenge for nurses is to support early identification of issues that can be addressed as part of a person-centred approach. The pyramid of psychological problems (Figure 2) (Trigwell et al 2008, NHS Diabetes and Diabetes UK 2010) conceptualises this increasing complexity. Individuals may move between levels over time, and validated assessment tools and open questions can be used to identify which level a patient is on.

Assessment tools can support nurses to explore diabetes-specific effects on patients’ well-being. They offer a starting point that can guide conversations, identify issues of particular importance and inform referral to specialist mental health support when required (Hendrieckx et al 2019). Changes from baseline measures can indicate improvements or deterioration in patients’ well-being (Hendrieckx et al 2019). There are several validated tools for the assessment of patient well-being that are specific to diabetes. The choice of tool should reflect the clinical purpose and ideally the same tool should be used to ensure consistency.

Healthcare professionals should also receive appropriate training in using assessment tools if required (Ali et al 2021).

**Problem Areas in Diabetes scale**
The Problem Areas in Diabetes (PAID) scale (Polonsky et al 1995) is a self-report measure of diabetes distress in the form of a 20-item questionnaire. Each item is rated on a five-point Likert scale from 0 (not a problem) to 4 (a serious problem). The total score is multiplied by 1.25 to generate a total score out of 100, with scores of ≥40 indicating severe diabetes distress (Polonsky et al 1995). An individual item score of ≥3 indicates a problem area or concern, correlating with level 1 of the pyramid of psychological problems (Figure 2) (Trigwell et al 2008, NHS Diabetes and Diabetes UK 2010).

According to Schmitt et al (2016), the PAID scale is preferable to other commonly used self-report measures because it ensures all of the person’s concerns are captured and assesses the effect of diabetes distress on their quality of life, in line with person-centred care. Reddy et al (2013) noted that the PAID scale has established validity for detecting diabetes distress in those with type 1 and type 2 diabetes, and provides an entry point for discussions, thus overcoming the difficulty some nurses and patients may experience in broaching issues related to well-being.

Chawla et al (2010) conducted a longitudinal pilot study to determine whether providing primary care physicians with the results of a PAID scale questionnaire completed by patients immediately before their consultation would improve patients’ glycaemic control and satisfaction. The findings suggested that this approach supported therapeutic dialogue and led to improved PAID scores and patient satisfaction. The authors concluded that the PAID scale can be useful in recognising crucial patient issues in primary care settings (Chawla et al 2010).

**Information prescriptions**
Information prescriptions are personalised advice and discussion tools. They can be embedded into primary care information...
technology systems or downloaded, and they can be introduced into the patient care pathway at any time (Diabetes UK 2017b). The Diabetes UK (2022) Mood Information Prescription aims to enable people with diabetes to talk about how they feel, manage their diabetes effectively and find practical ways to feel positive about living with the condition. This tool is available online at: www.diabetes.org.uk/professionals/news-updates/new-diabetes-and-mood-tool-for-clinicians. It can support a structured conversation about well-being and act as a conduit through which people can discuss their feelings with a nurse, potentially leading to treatment for low mood – often for the first time (Diabetes UK 2022).

Advising, assigning and arranging

Patients’ responses to tools such as the PAID scale can enable nurses to identify diabetes-specific factors related to well-being arising from the burden of managing the condition or a lack of social support (Martin et al 2018). Using open-ended questions, which can easily be integrated into routine consultations (Hendrieckx et al 2019), enables exploration and greater understanding of an individual’s issues. For example, a patient’s responses to the PAID scale might indicate a lack of social support, and this information – combined with the use of open-ended questions in a subsequent consultation – may identify that they would benefit from peer support groups. Alternatively, a patient’s responses and subsequent discussions might indicate that structured education programmes or access to technologies such as a wearable glucose monitoring device or insulin pump could be beneficial (Martin et al 2018). Nurses could also signpost or refer patients to group-based educational interventions, which can be effective in improving biopsychosocial outcomes for people with diabetes (Odgers-Jewell et al 2017). Facilitating effective psychological and behavioural change in a supportive environment can enable the development of individual and group-based change processes, leading to improvements in health outcomes (Borek et al 2019).

Scores of ≥40 on the PAID scale indicate severe diabetes distress (Snoek et al 2011) and may suggest levels 2–5 issues on the pyramid of psychological problems (Figure 2). Some nurses may not have the necessary skills or confidence to address this level of diabetes distress, so a referral to a mental health specialist for an in-depth psychological assessment may be required. Primary care networks should work in collaboration with mental health professionals to ensure that appropriate mental and emotional health screening is regularly undertaken for people with diabetes from the first point of contact, with clear referral processes in place (Ali et al 2021).

Increasing access to services for adults with common mental health issues, with a focus on those with short-term conditions, is an evolving process, and it is expected that primary care networks will work towards this type of integrated care for all people with diabetes (Ali et al 2021). However, many patients may prefer to continue to receive care from a primary care professional, so it is important that nurses in these settings continue to see patients for routine clinical visits following their referral for specialist care, to demonstrate their commitment to the patient’s ongoing management (Hendrieckx et al 2019).

Conclusion

Diabetes distress is commonly experienced by people living with the condition and is associated with suboptimal physical and mental health outcomes. Nurses need to be aware of the effects of the condition on patients’ well-being and are well placed to complete an initial assessment using open questioning and validated tools such as the PAID scale. Furthermore, nurses should act within the limits of their knowledge and skills and make onward referrals for specialist support or management as appropriate, while ensuring continued contact with patients to provide consistency and effective long-term monitoring and care.

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