KEY POINTS:

- Emotional or psychological problems are experienced by at least four in ten people with diabetes at any one time, yet less than a quarter of people with diabetes have access to appropriate emotional and psychological support.

- This reduces their ability and motivation to self-manage, leading to poorer health outcomes, reduced quality of life and an estimated 50% increase in healthcare costs.

- The psychological and emotional wellbeing of people with diabetes must therefore be an integral part of diabetes care delivery and should not be limited to people with ‘diagnosable/classifiable’ psychological problems.

Introduction

At least four in ten people with diabetes experience emotional or psychological problems, such as depression, anxiety and diabetes-related emotional distress¹. As a result, their ability and motivation to self-manage is reduced, leading to poorer health outcomes, reduced quality of life and an estimated 50% increase in healthcare costs (see page 3).

Yet all too often mental and physical health services are fragmented and people with diabetes lack access to appropriate emotional and psychological support.

The psychological and emotional wellbeing of people with diabetes must be an integral part of diabetes care delivery. Developing more integrated support on each step of the diabetes care pathway would help improve health outcomes and quality of life for people with diabetes and, in doing so, reduce healthcare costs.

SCOPE OF THIS STATEMENT

This position statement explores the need for emotional and psychological support for people living with diabetes. Although important, the needs of people with a severe mental illness who have or are at risk of developing diabetes are outside the scope of this statement.

Current situation

1) THE EMOTIONAL AND PSYCHOLOGICAL IMPACT OF DIABETES: UNMET NEEDS

Diabetes is a complex, demanding and progressive condition with potentially debilitating complications. Effective management is largely dependent on how people care for themselves; this requires constant personal motivation and changes in behaviour and
People with diabetes experience disproportionately high rates of emotional or psychological problems. It is estimated that around 40 per cent of people with diabetes experience poor psychological wellbeing at any one time. Depression is twice as common in people with diabetes as in the general population, while many people with diabetes have psychological needs that do not satisfy criteria for a formal diagnosis, which affects their ability to access psychological and emotional support services.

Often emotional distress is directly related to the impact of living with diabetes. Diabetes-related emotional distress, known as diabetes distress, reflects the emotional burden of self-management, threats of complications and potential loss of functioning. Two North American studies found a prevalence of around 42 per cent for at least moderate diabetes distress in adults with Type 1 diabetes and around 30 per cent in adults with Type 2 diabetes.

Diabetes is also associated with an increased risk of eating disorders, particularly among girls and young women with Type 1 diabetes. A longitudinal study suggests rates of over 30 per cent in women in their early twenties with Type 1 diabetes. The importance of emotional and psychological support for people with diabetes is recognised at a national level. NICE recommends that all adults with diabetes are assessed for psychological problems and sets out a stepped care model for managing depressive symptoms in adults with chronic physical health problems. For children and young people, the Paediatric Best Practice Tariff and NHS England’s Diabetes Transition Service Specification stipulate that access to psychological support should be integral to the diabetes multi-disciplinary team.

Yet current service provision falls far short of meeting the emotional and psychological needs of people with diabetes. A 2015 survey by Diabetes UK found that 76 per cent of people with diabetes had not been offered emotional or psychological support when they needed it. This echoes a previous survey of psychological provision for people with diabetes, which found 85 per cent of people with diabetes in the UK have either no defined access to psychological support and care, or at best access to a local generic mental health service only.

2) THE PYRAMID MODEL: UNDERSTANDING THE RANGE OF PSYCHOLOGICAL NEED

Many factors can affect the emotional and psychological wellbeing of a person with diabetes, including:

- the degree to which someone adjusts to their diagnosis
- coping with the constant demands of self-management and integrating this into existing life roles (e.g. parent, employee)
- developing an emotional resilience and flexible coping style to manage day-to-day challenges, setbacks and fears of complications
- coping with the progression of the condition, particularly when this includes diabetes-related complications
- for children and young people, their developmental stage can influence their ability to manage diabetes, which in itself can impact on their psychosocial development.

Psychological and emotional need can range from mild difficulties coping, through diabetes-related emotional distress, to severe psychological and psychiatric conditions. People with diabetes may have a different level of need at different points in their life. These may intensify with important life changes, such as transition from child to adult services, pregnancy or the development of complications.

The pyramid model (see page 3, figure 1) illustrates the range of psychological need present in the population and the broadly inverse relationship between prevalence and severity of need. It can be used by:

- healthcare professionals to identify the psychological needs of their patients at that particular time
- commissioners to identify the range of need within their population and commission services accordingly.
3) THE CONSEQUENCES OF POOR EMOTIONAL AND PSYCHOLOGICAL WELLBEING

Poor emotional and psychological wellbeing in people with diabetes is associated with poorer quality of life, greater difficulties with self-management and treatment adherence, sub-optimal glycaemic control and increased risk of complications. As a result, people with diabetes are almost 50 per cent more likely to die over a period of two to 10 years if they also have depression.

The relationship between diabetes and depression tends to be bidirectional: depression is associated with poor self-management and increased diabetes-related complications, which in turn contribute to psychological distress and depression.

These risks are not limited to people with a formal diagnosis of depression. People who experience depressive symptoms tend to have difficulties with self-management, even if they do not meet the diagnostic criteria for clinical depression. The more severe their symptoms, the poorer their ability to self-manage is likely to be. Even at low levels, diabetes distress is significantly related to glycaemic control and disease management.

Specific psychological conditions such as eating disorders, needle phobias and fear of self-injecting also lead to poor glycaemic control and subsequent complications.

Costs to the NHS are high. The independent Mental Health Task Force estimates that physical healthcare costs are 50% higher for people with Type 2 diabetes with poor mental health – costing an extra £1.8 billion every year. Likewise, a systematic review found that co-morbid mental health problems are consistently associated with an increase in total healthcare costs for people with diabetes, as well as increased indirect costs such as absence from work.

Although not the focus of this position statement, there are related issues with the physical health of people living with mental illness. People with severe mental illness die 15–20 years earlier on average than the general population, mainly as a result of physical ill health. The prevalence of Type 2 diabetes in people with schizophrenia, for example, is around two to three times higher than in the general population. Yet evidence suggests that diabetes patients with severe mental illness are less likely to receive standard levels of diabetes care.

4) DELIVERING EFFECTIVE SUPPORT SERVICES

Mental and physical health problems have traditionally been treated separately, with services designed around conditions rather than patients. Yet evidence suggests that treating emotional and psychological problems in isolation from an individual's diabetes does not always lead to improvements in physical health or self-management.
Indeed, as many as 30-40% of people with diabetes experience emotional distress directly related to the challenges of living with diabetes. These individuals are likely to respond best to interventions that target diabetes distress directly. Similarly, all people with diabetes, even with little or no emotional distress, can profit from ongoing acknowledgement, support and education about diabetes distress and coping strategies.

A USA-based study trialed the use of collaborative care management in primary care for people with depression, diabetes and/or coronary heart disease, integrating diabetes and heart disease treatment with support for self-management and care for depression. This collaborative care approach improved physical outcomes, including HbA1c, as well as control of depression and quality of life. The scale of these improvements compared favourably with results of interventions aimed at either depression or diabetes in isolation.

Another example of successful integration of physical and mental health care is south London’s 3 Dimensions of Care for Diabetes (3DfD) service, which brings together medical, psychological and social care for people with poorly controlled diabetes and complex psychological needs. The service provides brief, focussed interventions, guided by intensive case-management and patient-led case conferences. An evaluation found that this approach significantly improved glycaemic control, reduced psychological distress and reduced emergency attendances and unscheduled admissions.

The evidence presents a compelling case for person-centred care, removing the artificial divide between the emotional and the physical aspects of diabetes management and addressing the needs of the individual as a whole. The psychological and emotional wellbeing of people with diabetes must be an integral part of diabetes care and, to an appropriate degree, the responsibility of commissioners and care providers alike. Collaborative care planning is key to achieving this, helping identify and anticipate an individual’s need for emotional and psychological support in the context of their diabetes care.

Crucially, support must not be limited to people with ‘diagnosable/classifiable’ psychological disorders, as common problems such as diabetes distress or ‘sub-threshold’ depressive symptoms also have a negative impact on self-management, quality of life and health outcomes.

**Recommendations**

There is still a great deal of work to be done to achieve the aspirations set out in this position statement. In the short term, better use needs to be made of the existing mental health workforce to provide training and ongoing support for healthcare professionals working in diabetes. This would go some way towards equipping diabetes professionals with the skills necessary to provide an appropriate level of psychological and emotional support as part of routine practice.

However, achieving systemic change will require considerable investment in psychological services and workforce, as well as sustained effort both to integrate physical and mental health services and upskill professionals delivering diabetes care. More broadly, systems of care must allow clinicians working in diabetes, whether in primary or specialist care, time to build therapeutic relationships with their patients.

The independent Mental Health Taskforce strategy (2016) is a welcome step towards achieving this goal, driving home the importance of integrated care spanning physical, mental and social needs. It is vital that this strategy is now backed by clear leadership, practical action and appropriate funding at both a national and local level.

**NHS England** should:

- Drive system-wide integration of physical and mental health, not least by ensuring that this is a priority for new models of care and place-based commissioning approaches.
- Deliver the Mental Health Taskforce recommendation to increase access to evidence-based psychological therapies, with a focus on people who are living with long-term physical health conditions such as diabetes.

**Health Education England** should:

- Work with stakeholders to develop and deliver a comprehensive workforce strategy to ensure that the right staff with the right skills are available to meet the emotional and psychological needs of people living with diabetes, including:
  - core training in mental health skills for all healthcare professionals working in diabetes, including GPs and specialists
  - expanding the psychological workforce with expertise in diabetes, so that specialist psychological expertise is routinely available as part of the diabetes multi-disciplinary team (MDT) in both primary and specialist care.
Commissioners and service providers should work together to ensure:

- Emotional and psychological support for people with diabetes of all ages is embedded in each step of the diabetes care pathway and is not limited to people with 'diagnosable/classifiable' psychological problems.

- Appropriate services are available locally to meet the varying emotional and psychological needs of people with diabetes of all ages, in line with the pyramid model. This should include timely access to Improving Access to Psychological Therapies (IAPT) interventions, with specific care pathways for diabetes.

- Interventions to support self-management are designed to consider and address the emotional and psychological impact of diabetes.

- Healthcare professionals working in diabetes, in both primary and specialist care, have training and ongoing supervision to identify and provide proactive support for psychological and emotional problems as part of routine clinical care — including through the use of screening tools and care planning.

- Diabetes specialists have specialist psychological expertise* integrated into the diabetes MDT, both for referral and to supervise/support the team to identify and provide care for emotional and psychological problems.

- GPs and primary care professionals have access to specialist psychological expertise* for advice, support and collaborative case management as needed.

- Mental health professionals providing emotional and psychological support for people with diabetes, such as IAPT workers, have specific training in diabetes.

- Healthcare professionals have the time and resources to work in partnership with people with diabetes through the care planning process.

Healthcare professionals in both primary and secondary care need to:

- Consider emotional and psychological support part of the remit of the whole MDT.

- Ensure they have adequate training and supervision to identify psychological problems in people with diabetes and deliver an appropriate level of proactive support as part of ongoing diabetes care, including through the care planning process.

- Be familiar with the emotional and psychological support services available to their patients, both locally and through national organisations such as Diabetes UK (see below for Diabetes UK support).

Further information

SUPPORT FOR PEOPLE WITH DIABETES AND HEALTHCARE PROFESSIONALS

Diabetes UK provides a range of support services for people with diabetes, including:

- **Helpline** (formerly Careline) — specialist information and advice on all aspects of living with diabetes (by phone or email).

- **Local support groups** — offer people living with diabetes a chance to meet and share experiences with others in their area.

- **Online Communities** — a place to find support and discuss issues with other people with diabetes.

For more information about these services go to [www.diabetes.org.uk/talk](http://www.diabetes.org.uk/talk)

COMMISSIONING AND POLICY RESOURCES


Diabetes UK (2014): *Three dimensions for diabetes (3DFD)*: Case study of the 3DFD service at King’s

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*Specialist psychological expertise: mental health professionals who can deliver complex psychological interventions i.e. clinical or counselling psychologists, in some services liaison psychiatry.*
College Hospital Foundation Trust that integrates diabetes, psychological and social interventions for people with complex psychological needs.

London Strategic Clinical Networks (2014): London’s diabetes care pathway - commissioning recommendations for psychological support
Includes case studies of effective services. London-focused but relevant to decision makers across the UK.

NHS England Diabetes Transition Service Specification January 2016. Sets out a best practice service provision model for commissioners of services for young people with diabetes up to the age of 25, including integrated psychological support.

Other resources are available from the Diabetes UK shared practice library.
References

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