Identifying and managing diabetes distress

Not mad, more likely sad

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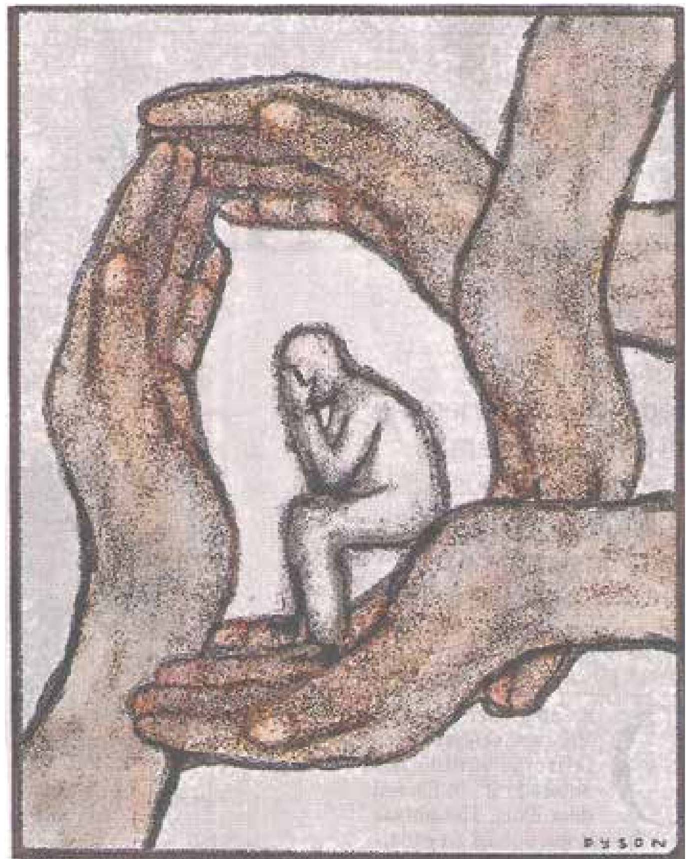
Diabetes distress affects a large proportion of people with diabetes and is associated with compromised self-management behaviours and poorer diabetes outcomes. Identifying high levels of diabetes distress early using a short questionnaire or by raising the issue in conversation with the patient enables specific targeted interventions to improve diabetes care and control and prevent worsening of symptoms.



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Key points

- **Diabetes distress is a common, nonpathological emotional reaction to the stresses of chronic illness.**
- **Diabetes distress is associated with impaired capacity for self-management and poorer biomarkers for diabetes health.**
- **Diabetes distress is often confused with depression and it is important to differentiate between the two to ensure appropriate interventions.**
- **Simple tools are available to identify diabetes distress in routine clinical practice.**
- **Treating diabetes distress within the diabetes care team has a significant positive impact on outcomes.**

ENDOCRINOLOGY TODAY 2015; 4(2): 21-23

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Diabetes distress is a common problem for people with diabetes and often has a significant negative impact on self-management and health outcomes. General practitioners have the opportunity to identify diabetes distress during discussion about diabetes care in routine consultations. Early identification and management of diabetes distress has the potential to alleviate emotional symptoms, lessen risk of progression to depression, mitigate negative effects on self-management, enhance healthcare professional–patient communication and increase healthcare professional satisfaction.

What is diabetes distress?

The psychological and emotional complications of serious medical conditions, such as diabetes and cancer, have long been recognised as distinct from mental health issues, such as depression and anxiety.[1,2] Illness-specific psychological distress has been helpfully described as the essentially healthy reactions of ordinary people struggling to master a novel and burdensome situation.[3]

Diabetes-specific distress is not considered to be a pathological disorder or mental health problem. Rather, diabetes distress originates in the nature of the medical condition and the demands on the patient – the grief over actual and anticipated losses, the complex challenges and burden of self-management, the emotional and social consequences, the impact on identity and self-perceptions, and the ongoing uncertainty and fear of complications.[1,4] Although there are many similarities in the psychological challenges of chronic medical illnesses, diabetes places a unique and distinct set of demands on the people who live with it. As technological advances provide welcome incremental improvements in devices, medications and information, the complexity of treatment falling to the individual and their families grows. This burden of daily and hourly self-management responsibility, which is shared by few other illnesses, has been likened to holding down a second job.[5]

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Table 1. Major areas of diabetes distress and examples of specific issues and suggested strategies

Major areas of diabetes distress	Specific issues	Suggested strategies
Emotional burden	• At diagnosis, anniversary effects as people realise diabetes is a chronic disease[9] • Guilt, anger, frustration, burnout[10] • Depressive symptoms, anxiety	• Normalise and validate emotional reactions • Reassure patient that diabetes distress is common and fluctuates over time • Poor communication at diagnosis is associated with later diabetes distress[11] • Check on possible distorted diabetes beliefs and expectations based on family history, other personal experience and media exposure
Regimen distress	• Changes of treatment – psychological insulin resistance in type 2 diabetes[12] – shift to insulin pump – injection or laser therapy for retinopathy	• Reassure patient that reactions are common and normal • Use decision aid tools to assist in active treatment participation[13] • Try to arrange for social support to alleviate task burden for a temporary diabetes vacation
Interpersonal relationships – family/friends – healthcare professionals	• Interpersonal distress (or miscarried helping) from family and friends[8] • Poor communication of healthcare professionals, not engaging in collaborative care[14]	• Involve family members, if possible/preferred in consultations • Develop social support – protective for people with type 2 diabetes on insulin[15] • Assertiveness skills training, question prompt sheets, shared decision-making[14]
Fear of complications – short term: hypoglycaemia – long term: macrovascular and microvascular complications	• Major fears at diagnosis[10] • Major fears with increase in HbA_{1c} • Major fears before screening for complications • Major fears at diagnosis of early nonproliferative diabetic retinopathy, peripheral neuropathy, microalbuminuria • Predialysis, transplant listing, amputation, significant vision loss	• Check understanding and educate patient about risk and associations between blood glucose levels, HbA_{1c} and complications • Address potential guilt feelings • Educate about screening procedures and debrief results • Use online risk assessment tools if appropriate (e.g. UKPDS Risk Engine) • Check patient understanding/interpretation of results • Grief counselling Note: in-range HbA_{1c} not necessarily protective for diabetes distress

These psychological responses to being diagnosed and living with diabetes overlap with, and may be easily mistaken for, depressive symptoms or diagnosed as depression.[6] However, it is important to distinguish among these because diabetes distress has the stronger relationship with diabetes self-care and glycaemic control.[7]

Specific components of diabetes distress are detailed in Table 1 along with suggested strategies for intervention and management. Interpersonal distress, referred to as miscarried helping, is defined as support attempts from family or friends that are excessive, untimely or inappropriate.[8-15] In practice, difficult interactions with others may include questions such as ‘Should you be eating that?’ or comments along the lines of ‘at least it’s not cancer’ that are stressful for any person with diabetes, as well as parents and other family members.

People with diabetes view the risk of major long-term complications as one of their major concerns at diagnosis and long term.[10,16] Patients tend to significantly overestimate their risk for long-term complications[17,18] and experience significant anxiety related to distorted perceptions. For example, parents of children with type 1 diabetes believe that nonadherence with the diabetes regimen ensures long-term complications rather than increasing their risk.[19]

Diabetes distress is common

Diabetes distress is common in people with diabetes of all ages, with type 1 or type 2 diabetes, whether using insulin or not. Prevalence estimates differ according to the assessment method, type of diabetes and type of treatment and country;[9,20,21] however, approximately 45% of people with diabetes worldwide report significant distress associated with their diabetes that exerts a significant negative impact on other aspects of life including relationships and physical health.[22] Family members, including spouses and partners as well as parents and siblings, also experience diabetes distress. In a large multinational study of relatives, 35% perceive supporting a relative with diabetes as a burden.[23]

Consequences of diabetes distress

Diabetes distress is strongly associated with poorer self-care behaviours (eating, exercise, monitoring blood glucose levels, screening for complications) as well as higher HbA_{1c} levels.[7,21] The following two case studies help to illustrate these associations.

- *Ruth, a 21-year-old woman with type 1 diabetes, experienced difficulties in handling the reactions of others in social*

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Table 2. Two-item Diabetes Distress Scale (DDS2)*

Item	Not a problem	A slight problem	A moderate problem	A somewhat serious problem	A serious problem	A very serious problem
1. Feeling overwhelmed by the demands of living with diabetes	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine	1	2	3	4	5	6

* The DDS2 is a two-item diabetes distress screening instrument asking respondents to rate on a six-point scale the degree to which the two items above caused distress. An average score of <2 indicates little or no distress, a score between 2 and 2.9 indicates moderate diabetes distress and ⩾3 indicates high level of diabetes distress.

situations related to taking her insulin or checking blood glucose levels. Coping with her embarrassment by simply not performing these self-care behaviours compromised her diabetes control over several years. Seeking help and learning assertiveness strategies helped to change her behaviours and improve her diabetes outcomes.

- *Mary, a 61-year-old woman with a six-year history of type 2 diabetes, was advised to consider insulin as the next step in her treatment. She was highly reluctant to do so for some time and her HbA$_{1c}$ deteriorated. Once her distorted beliefs about insulin and complications associated with her family history of diabetes were identified and addressed thoroughly, Mary was able to initiate insulin and her HbA$_{1c}$ improved.*

Several recent studies have shown improvements in distress and depression symptoms and HbA$_{1c}$ with interventions aimed at diabetes distress rather than targeting depression.[24,25]

Diagnosing diabetes distress

People with diabetes are not always familiar with the symptoms and diagnosis of diabetes distress. Patients with diabetes distress may be troubled by their symptoms but be reluctant to raise concerns due to stigma and fears of being labeled. Patients may also present as frustrated with their capacity to implement self-care and feel guilty for not managing as well as they perceive they should. A frequent comment is 'I know what to do, I just can't seem to do it'. Identifying clinically significant diabetes distress may occur in ongoing conversations about diabetes care by asking questions such as 'How is diabetes bothering you at the moment?' Raising the issue normalises the topic, helps patients to see that diabetes distress is connected to the medical management of diabetes and is not a separate mental illness issue, and reduces stigma.[6]

Diabetes distress may be mistaken for depression as there can be overlap in symptoms. Differentiating the basis of symptoms is also complicated by the fact that some depression symptoms may be accounted for by hyperglycaemia.[6] Ideally using the two-item Diabetes Distress Scale, which is recognised as a reliable screening tool for identifying people experiencing significant levels of diabetes distress (Table 2),[26] together with a validated brief measure of depression enables the clinician to detect both significant diabetes distress and depression symptoms. However, patients themselves are usually quite capable of discerning the difference if a pragmatic approach to this issue is taken. A useful question is 'If you didn't have diabetes, would you still feel like this?' Most people with diabetes distress will quickly say no.

Management

The main components of diabetes distress with their specific challenges and triggers experienced during the course of diabetes, along with suggested strategies and approaches are outlined in Table 1. These conversations are within the scope of most diabetes healthcare professionals and patients prefer to have these issues addressed by familiar clinicians. For more complex problems or if time constraints dictate referral as the preferred option, appropriate interventions designed for nonpathological psychological issues in the context of medical illness include diabetes-specific cognitive behaviour therapy[27] and medical crisis counselling.[3,28] Consider referral of the patient to a health psychologist who is familiar with taking a nonpathological approach rather than a mental health stance and preferably someone with experience in diabetes team care. Patients prefer and are more likely to follow up with such a clinician.[29]

The small subset of patients who have major depression in addition to experiencing significant diabetes distress need to be treated for both these conditions, which will involve distinct intervention approaches. It is important to note that treating diabetes distress inappropriately as depression risks delaying improvements in diabetes self-management behaviours and control with potentially compromised health outcomes.[6]

Conclusion

Diabetes distress is very common in people with diabetes and is associated with impaired capacity for self-management. Interventions delivered in the general practice and diabetes care settings focused on normalising and managing emotional reactions to diabetes, informed decision-making, problem solving and improving communication with family and friends have the potential to alleviate potential negative effects of diabetes distress. Referral of the patient, if required, is best offered within a non-mental health framework. **ET**

References

A list of references is included in the website version (www.medicinetoday.com.au) of this article.

COMPETING INTERESTS: None.

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