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Monitoring psychological well-being of people living with diabetes: how to implement in clinical practice?

Living with diabetes impacts psychological well-being

Diabetes is one of the most challenging, demanding and costly chronic conditions. There is strong evidence that people of all ages living with diabetes are more distressed and have more depressive symptoms than the general population. Systematic reviews report the prevalence of depressive symptoms in type 1 and type 2 diabetes to be two to three times higher than in people without diabetes.\(^3\) This means that two to four in every ten people with diabetes attending a GP or diabetes clinic are likely to be depressed or experiencing subclinical levels of depression. Depressive symptoms are associated with chronic hyperglycaemia, early diabetes complications and more frequent hospitalisations; and also with impaired quality of life and self-care behaviours.

Results from the Diabetes MILES – Australia 2011 Survey demonstrated that adults with insulin-treated type 2 diabetes were most likely to experience moderate-to-severe depressive symptoms (35%) compared to adults with type 1 (22%) or type 2 non-insulin treated (23%), while people with type 1 diabetes were more likely to experience severe diabetes-related distress (28%) than people with type 2 diabetes (22% insulin treated, 17% non-insulin treated)\(^3\). Daily diabetes care is demanding. Injecting insulin, taking oral medications, monitoring blood glucose levels, getting regular physical activity and healthy eating can only be maintained with unwavering motivation and resilience. These continual efforts have few short-term benefits and are not always rewarded with optimal biomedical outcomes, which can lead to further negative emotions: frustration, anger, guilt and worry. Early recognition of depressive symptoms and diabetes-related distress is crucial.

Early recognition of emotional problems needs to be part of routine diabetes care

Routine monitoring of psychological well-being in people with diabetes has been recommended for almost 20 years in international guidelines (St Vincent’s Declaration (1994), the International Diabetes Federation (IDF) Guidelines for Diabetes Care (1998)) and the American Diabetes Association (ADA) standard of medical care (2006). However, implementation in clinical practice remains sporadic and fragmented. Barriers to routine monitoring of psychological well-being are commonly considered to include time and a general reluctance to ‘open Pandora’s box’. Healthcare professionals often feel uncomfortable talking about emotions. As a consequence, psychological problems, such as diabetes-related distress, can remain unrecognised and untreated. In one study, only one in four cases of diabetes-related distress in people with diabetes were recognised by their healthcare professionals\(^4\), suggesting that impaired well-being is likely to remain undetected without systematic and routine monitoring.

Routine monitoring of well-being is both feasible and effective

Randomised trials and observational studies conducted in outpatients diabetes clinics have demonstrated that monitoring well-being and discussing the results as part of routine practice improves psychological well-being in adults\(^5,6\) and adolescents\(^7\), and glycaemic control in adults\(^5\). The assessment was positively evaluated by both patients and healthcare providers. People with diabetes feel a need to talk about their emotions with their healthcare providers, and this is more pronounced in those who experience high levels of psychological distress, suggesting that those who need to talk are those that want to talk\(^8\).

How and when should we monitor psychological well-being in clinical practice?

Brief, easy-to-use, and valid questionnaires are freely available for clinical use. The “Problem Areas in Diabetes” scale\(^9\) and the “Diabetes Distress Scale”\(^10\) assess specific problem areas related to diabetes treatment, emotions,
support and lifestyle issues. Outcomes can be reviewed at an item level or as a total score. A total score above a designated cut-off indicates severe diabetes-related distress, while item scores provide an indication of specific problems, which can provide a starting point for discussion. Brief measures, e.g. the WHO-5 well-being index and Patient Health Questionnaire-9 (PHQ-9), are also available for assessing depressive symptoms. These measures are not diagnostic tools and diagnosis needs to be confirmed by clinical interview. However, these are valid tools for pro-active identification of people at risk for emotional problems.

Routine monitoring of well-being can be implemented as part of the annual review. More frequent assessments are recommended if major problems are identified and a treatment plan is needed. Computerised monitoring has several advantages: questionnaire completion is convenient; total scores and interpretation are available for discussion immediately; outcomes can be stored alongside biomedical outcomes in the electronic health records for future review.

**Addressing emotions and concerns during consultations**
If a questionnaire has been used, asking about the item(s) scored as most problematic is a good way to begin the consultation. If a questionnaire has not been used, then starting the consultation with open questions invites the person to raise any concerns. Questions such as “what is the most difficult part of living with diabetes for you?” or “what are your greatest concerns about your diabetes?” will help in making consensus decisions about what actions and changes are going to be likely to achieve better biomedical outcomes and reduce the emotional burden of managing diabetes. This person-centred, open communication has been shown to increase both the patient’s and healthcare professional’s satisfaction with the care provided. The disadvantage is that this method is not standardised and no numerical value is available to monitor changes over time. But if systematic monitoring is considered “unrealistic” in your setting, this alternative offers a person-centred approach to the consultation.

**Identifying psychological problems: what next?**
Healthcare professionals are often concerned that monitoring will identify large numbers of people with psychological problems, for whom help may be unavailable, as mental health services are scarce. These assumptions are largely untrue.

First, most people with diabetes cope reasonably well with the condition, with the exception of major changes in personal circumstances (e.g. divorce) or in their diabetes (e.g. changes in treatment or in complication status). Such issues can temporarily lead to greater emotional burden and need for additional support from the healthcare team in managing their diabetes. Second, a substantial number of people identified as having emotional problems already receive specialised care. Referrals to mental health specialists must be considered for psychiatric disorders, e.g. eating disorders, personality disorders or recurrent major depression. Third, few emotional problems related to diabetes require referral to mental health specialists. Diabetes-related distress typically concerns treatment-related issues, anxiety about future complication risk or difficulty coping, and can be dealt with very well with support from the GP, endocrinologist or diabetes educator. Recognising and normalising diabetes-related distress can lead to relief and better well-being. It will also contribute to strengthening mutual trust and confidence. Even the apparent presence of depressive symptoms may not require referral to mental health specialists, as much of the variance in such symptoms is accounted for by diabetes-related distress.

Finally, there is no good evidence that addressing emotions necessarily lengthens consultations. However, even if it does initially prolong consultations, in the long-run it will be more clinically- and cost-effective. Empathic response has been shown to impact positively on self-care behaviours, reduce distress, strengthen self-confidence and improve biomedical outcomes.
Conclusions
The reciprocal relationship between diabetes and emotional well-being has been clearly documented. The feasibility and effectiveness of systematic monitoring of psychological well-being and discussing outcomes has been demonstrated, and is recommended in several international guidelines. It is time to implement psychological assessment as part of routine clinical practice. Having the opportunity to express emotions, concerns and behavioural difficulties – and to have those normalised – is a crucial element of a person-centred model of care, and vital for informing individually tailored treatment plans.

Key point messages
1. Monitoring psychological well-being and discussing outcomes needs to be an integral part of routine diabetes care
2. Normalising the emotional consequences of living with diabetes leads to better well-being and opportunity to improve diabetes outcomes

Word count 1232

Further reading

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No conflict of interest declared
Further details about measures of psychological well-being are available from the author: chendrieckx@acbrd.org.au
References


