

## Invited Review

# Addressing diabetes distress in clinical care: a practical guide

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### Abstract

Addressing the emotional side of diabetes and its management has received considerable attention in recent years. At the centre of most of these efforts is the concept of ‘diabetes distress’, a generic term that captures the primary sources and intensity of emotional distress associated with diabetes and its management over time. As interest in diabetes distress has grown, however, it has been difficult to integrate and translate the various strands of clinical research in a manner that can guide diabetes distress intervention efforts in the real world of clinical care. The aim of this paper is to fill this gap by outlining practical strategies for intervention in clinical settings and to assist diabetes healthcare professionals in thinking through how diabetes distress might be addressed practically in their clinics. To address these goals, this review is divided into five sections: a definition of diabetes distress, ways diabetes distress can be assessed and monitored, information about diabetes distress for use in intervention planning, topics to be considered for inclusion in diabetes distress interventions, and alternatives for where in the care process a diabetes distress intervention might be considered. We focus on diabetes distress experienced by adults with both Type 1 and Type 2 diabetes.

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### Introduction

Addressing the emotional side of diabetes and its management has received considerable attention in recent years [1]. Although a focus on management, action planning and other behavioural aspects of lifestyle change remain the primary targets of current clinical intervention, there has been increased recognition that diabetes brings with it a host of emotional and distress-related experiences that directly affect both behavioural management and quality of life, and that these experiences need to be attended to as part of comprehensive diabetes care [2,3].

At the centre of most of these efforts is the concept of ‘diabetes distress’, a generic term that captures the primary sources and intensity of emotional distress associated with diabetes and its management over time [4]. As interest in diabetes distress has grown, however, it has been difficult to integrate and translate the various strands of clinical research, including both interventional and non-interventional studies, in a manner that can guide intervention efforts in the real world of clinical care. The aim of this review is to fill this gap by outlining practical strategies for intervention in clinical settings and to assist diabetes healthcare

professionals in thinking through how they might be utilized practically in their clinics. To address these goals, this report is divided into five sections: a definition of diabetes distress, ways in which diabetes distress can be assessed and monitored, information about diabetes distress for use in intervention planning, strategies to be considered for inclusion in diabetes distress interventions, and options in the care process where a diabetes distress intervention might be considered. We focus on diabetes distress experienced by adults with either Type 1 and Type 2 diabetes.

### Defining diabetes distress

Diabetes distress refers to the worries, concerns, fears and threats that are associated with struggling with a demanding chronic disease like diabetes over time, including its management, threats of complications, potential loss of functioning and concerns about access to care [5]. Diabetes distress is an expected response to having diabetes: it does not necessarily imply psychopathology and it is not viewed as a comorbid disorder or condition; it is simply the emotional side of having diabetes [6]. With this in mind, we have argued that diabetes distress is most effectively addressed as part of comprehensive diabetes care by diabetes healthcare providers and not viewed as a ‘condition’ that

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**What's new?**

- As interest in diabetes distress has grown it has been difficult to integrate and translate the various strands of clinical research in a manner that can guide diabetes distress intervention efforts in the real world of clinical care.
- We outline practical strategies for intervention in clinical settings to assist diabetes healthcare professionals in thinking through how diabetes distress might be addressed practically in their clinics: programmes for highly distressed individuals; programmes centred around diabetes-specific events, including information about distress to programmes of diabetes education; and incorporating distress content into all clinical contacts.
- We also provide a five-step programme on distress content for use in clinical settings: assess distress regularly and systematically, focus on feelings and expectations, provide a new perspective, plan and follow-up.

should be referred to others outside the diabetes treatment setting.

Diabetes distress can show itself in many forms and may be influenced by age, gender, culture, type of diabetes, use of insulin, number of complications and time with diabetes [7]. Common elements include feelings of powerlessness and hopelessness, fears of hypoglycaemic episodes or complications, high levels of 'burnout' because of the unrelenting management tasks and frustration with care providers (often leading to distrust, hostility, missed appointments). The sources of diabetes distress vary between individuals with Type 1 and Type 2 diabetes, based on the different demand characteristics of each [8,9]. For example, fears of hypoglycaemia and feelings of powerlessness may be more pronounced among adults with Type 1 diabetes than among those with Type 2 diabetes on oral medications only.

Although modestly associated with poor glycaemic control, elevated diabetes distress is not restricted to those having problems managing their disease; indeed, high diabetes distress can occur among those in good metabolic control [5]. This highlights the impact of the unrelenting management burden or the ongoing fear of what the future might bring, reflecting the ubiquity of diabetes distress across the diabetes population. Furthermore, how diabetes distress is expressed and experienced can vary over time, even within the same individual, and can increase in conjunction with crucial diabetes events [10]. Lastly, addressing diabetes distress should be considered even among those who are currently not experiencing significant levels of diabetes distress [11]. Doing so informs the person with diabetes that

you as a healthcare provider are as concerned about their personal experience of diabetes as you are about their blood glucose numbers, it opens the door to discussions at other times when diabetes distress may be experienced, and it serves to help persons with diabetes anticipate emotional reactions to diabetes-related events that might occur in the future.

## Assessing diabetes distress

Diabetes distress is assessed most practically using brief, self-report surveys. Below, we review three of the most commonly used measures, with a summary presented in Table 1. Using a structured scale is time-efficient, quantitative, can be used to monitor change over time and provides concrete findings that can be shared with people with diabetes. Although screener versions of these scales have been published [12,13], we focus here on use of the entire scale. This is because variation in sources of distress among different individuals, as reflected by the various subscales, prompt different kinds of clinical conversations. To illustrate, in Table 1 we include the percentage of individuals who completed either the Type 1 Diabetes Distress Scale (T1-DDS) or the Diabetes Distress Scale (DDS) and who reached criteria for 'clinically significant' distress on each subscale, using a mean item subscale score of  $\geq 2.0$  [8,14]. These percentages highlight the variability of sources of distress among both Type 1 and Type 2 populations.

### Problem Areas in Diabetes

Problem Areas in Diabetes (PAID) a 20-item scale that was standardized primarily with adults with Type 1 diabetes [15]. Items are scored on a 5-point Likert scale, from 'not a problem' to 'a serious problem' and are summed to yield an overall diabetes distress score that can be easily converted to a scale from 0 to 100 [15]. Scores  $\geq 40$  and above are considered 'significant diabetes distress' [16]. The PAID yields only a total, overall diabetes distress score; no subscale scores are available to help identify specific sources of diabetes distress. The PAID is used widely and is available in multiple languages.

### Diabetes Distress Scale

The DDS was standardized primarily with adults with Type 2 diabetes [9]. It was developed to identify key sources of diabetes distress, rather than, as in the PAID, focusing exclusively on an overall diabetes distress score. It contains 17 items, each rated on a 6-point Likert scale, from 'not a problem' to 'a serious problem'. The scale yields a total diabetes distress score, plus scores for four subscales: emotional burden, regimen distress, physician distress and interpersonal distress. Each subscale can be administered

**Table 1** Commonly used measures of diabetes distress

Scale	Description	No. items	Scoring	Cut-off point for significant distress	Per cent with significant distress
PAID: total score; standardized primarily with adults with Type 1 diabetes	Overall distress across all sources	20	Summed items converted to 0–100 scale	≥ 40	
DDS: total score; standardized primarily with adults with Type 2 diabetes	Overall distress across all sources	17	Mean item score (1–6)	≥ 2 moderate or high distress	40.0
Emotional burden	Feeling overwhelmed, frightened or fearful about managing the demands of diabetes over time	5	Mean item score (1–6)	≥ 2 moderate or high distress	44.9
Physician distress	Worries about health care and obtaining sufficient expertise, support and direction from healthcare providers	4	Mean item score (1–6)	≥ 2 moderate or high distress	26.5
Regimen distress	Feeling that they are failing by not managing their diabetes well, e.g. meal plan, exercise	5	Mean item score (1–6)	≥ 2 moderate or high distress	60.0
Interpersonal distress	Feeling that they are not receiving sufficient support for their diabetes among family and friends.	3	Mean item score (1–6)	≥ 2 moderate or high distress	34.5
T1-DDS: total score; standardized exclusively with adults with Type 1 diabetes	Overall distress across all sources	27	Mean item score (1–6)	≥ 2 moderate or high distress	42.0
Powerlessness	A broad sense of feeling discouraged about diabetes; e.g. 'feeling that no matter how hard I try with my diabetes, it will never be good enough'	5	Mean item score (1–6)	≥ 2 moderate or high distress	71.5
Management distress	Disappointment with one's self-care efforts; e.g. 'feeling that I don't give my diabetes as much attention as I probably should'	4	Mean item score (1–6)	≥ 2 moderate or high distress	44.2
Hypoglycaemia distress	Concerns about severe hypoglycaemic events; e.g. 'feeling that I can't never be safe from the possibility of a serious hypoglycaemic event'	4	Mean item score (1–6)	≥ 2 moderate or high distress	42.8
Negative social perceptions	Concerns about the possible negative judgments of others; e.g. 'feeling like I have to hide my diabetes from other people'	4	Mean item score (1–6)	≥ 2 moderate or high distress	32.9
Eating distress	Concerns that one's eating is out of control; e.g. 'feeling that thoughts about food and eating control my life'	3	Mean item score (1–6)	≥ 2 moderate or high distress	54.3
Physician distress	Disappointment with one's current healthcare professionals; e.g. 'feeling that I don't get help I really need from my diabetes doctor about managing diabetes'	4	Mean item score (1–6)	≥ 2 moderate or high distress	12.1
Friend/family distress	A perception that there is too much focus on diabetes amongst one's loved ones; e.g. 'feeling that my family and friends make a bigger deal out of diabetes than they should'	4	Mean item score (1–6)	≥ 2 moderate or high distress	22.7

PAID, Problem Areas in Diabetes; DDS, Diabetes Distress Scale; T1-DDS, Type 1 Diabetes Distress Scale. T1-DDS percentages ( $n = 414$ ) [46]; DDS percentages ( $n = 506$ ) [14].

independently. Total and subscale scores are calculated using mean item scores, which are then categorized as little or no distress (< 2.0), moderate distress (≥ 2.0 and ≤ 2.9) and high distress (≥ 3.0). Moderate and high distress are considered

'clinically significant' [14]. Like the PAID, the DDS is available in multiple languages. Online administration, scoring and summary reporting of the diabetes distress (in English and Spanish) are available at [diabetesdistress.org](http://diabetesdistress.org).

### Type 1-Diabetes Distress Scale

The T1-DDS was standardized exclusively with adults with Type 1 diabetes [8]. It is a 28-item scale that yields an overall distress score, plus seven subscale scores that address common sources of diabetes distress found among adults with Type 1 diabetes: powerlessness, management distress, hypoglycaemic distress, negative social perceptions, eating distress, physician distress and friend/family distress. Each subscale can be administered independently. Items are scored on a 6-point Likert scale, from 'not a problem' to 'a serious problem' and, like the diabetes distress, mean item scores are categorized into little or no distress (< 2.0), moderate distress ( $\geq 2.0$  and  $\leq 2.9$ ) and high distress ( $\geq 3.0$ ). Moderate and high distress scores are considered 'clinically significant' [8]. The T1-DDS is also available in multiple languages (behavioral diabetes.org), and for automated, web-based administration (in English and Spanish) at diabetesdistress.org.

In general, the PAID is an excellent measure of overall diabetes distress: it covers a greater variety of distress content than the DDS, and it is more strongly correlated with dysfunctional coping styles, quality of life and depressive symptoms than the DDS [17]. By contrast, the DDS and T1-DDS display larger associations with management and metabolic outcomes than the PAID [17]. All the scales and subscales demonstrate good validity and reliability.

The PAID may best be used primarily with adults with Type 1 diabetes, because these were the population included in the original standardization sample. The DDS and T1-DDS may be most clinically useful for adults with Type 1 or Type 2 diabetes, respectively, because of their original standardization samples. Furthermore, both the DDS and the T1-DDS contain reliable and valid subscales that can be used to identify the different sources of distress and facilitate targeted interventions. Online access and web-based administration and reporting may also make the DDS and T1-DDS more useful clinically.

### Information about diabetes distress for use in intervention planning

In this section, we provide a brief overview of essential information about diabetes distress. First, in large-scale studies using diverse community samples in the USA, Fisher *et al.* reported a prevalence of 'significant' diabetes distress of around 42% for adults with Type 2 diabetes and around 43% for adults with Type 1 diabetes [18,19]. Perrin *et al.* reported a prevalence rate for individuals with Type 2 diabetes of 36%, following a meta-analysis of several studies [20]. But these rates vary substantially across different groups of adults with diabetes, and perhaps across countries with different healthcare systems: rates tend to be higher for women, relatively younger adults, those on insulin, those with poor glycaemic control, high BMI, long diabetes duration or significant diabetes comorbidities [7,21,22].

They also tend to be much lower among adults with either Type 1 or Type 2 diabetes in primary care with good glycaemic control, e.g. < 10% [7]. In any case, these rates are significant as well as troubling.

Second, although highly responsive to intervention [1], unaddressed diabetes distress can become chronic over time and even may increase in intensity [18,19]. For example, in one study of adults with Type 1 diabetes with elevated diabetes distress at baseline, 74% continued to report elevated diabetes distress at 9 months [18]. Similar findings have been reported for those with Type 2 diabetes [19]. Thus, diabetes distress does not typically disappear when left unaddressed.

Third, it is important to distinguish diabetes distress from clinical depression or major depressive disorder. Most people with diabetes labelled as clinically depressed using common self-report inventories (e.g. Patient Health Questionnaire-9; PHQ-9) [23] do not meet standard psychiatric criteria for major depressive disorder [2]. When well-structured psychiatric interviews are undertaken with most samples of adults with diabetes, however, the prevalence of major depressive disorder distress falls to between 3.8% and 6%, which is similar to rates in the general community [6,24] (note variation in this rate based on clinical setting and an individual's characteristics). Still, individuals with diabetes typically score higher on depression symptom measures than people who do not have diabetes, and although these higher scores may not be indicative of a depressive disorder, they do reflect the experience of significant emotional distress. In recent studies, depressive symptom scores, using the PHQ-9, have been found to correlate quite highly with diabetes distress scores (e.g.  $r$  as high as 0.60), pointing to a significant overlap between these two constructs [25]. Furthermore, in one study, initial analyses indicated significant associations between depressive symptoms with management and HbA<sub>1c</sub>; but when diabetes distress scores were entered into the same analysis, depressive symptom scores were no longer significantly associated with these outcomes, whereas diabetes distress scores were [26]. We suggest, therefore, that clinicians should not immediately assume that elevated depression symptom scores obtained from self-report inventories are indicative of a depressive disorder. Instead, it is likely that such scores reflect the emotional distress associated with diabetes [27,28]. This is not to say that major depressive disorder does not exist in diabetes populations. When it is carefully documented and diagnosed, it needs to be treated accordingly.

Fourth, although elevated levels of diabetes distress have been linked to poorer self-management and glycaemic control in adults with Type 1 or Type 2 diabetes [9,29–31], intervening on diabetes distress alone may not lead directly to improvements in self-management or glycaemic control [32]. There is an important distinction to be made between cross-sectional associations between diabetes distress and self-management or HbA<sub>1c</sub> at one point in time, and how change in diabetes distress through intervention

affects change in management or HbA<sub>1c</sub> over time. Two studies, one including adults with Type 1 and the other with Type 2 diabetes, highlight this distinction [32,33]. Both showed significant and clinically meaningful cross-sectional associations between diabetes distress and self-management and HbA<sub>1c</sub> at baseline, prior to intervention. However, both also showed that associations between changes in diabetes distress and changes in self-management and HbA<sub>1c</sub> over time as a result of intervention although statistically significant, were only modest. These findings suggest that reductions in diabetes distress as a result of intervention may not, in and of themselves, lead directly to significant improvements in self-management or glycaemic control [34]. It may be the case that elevated diabetes distress serves as a barrier that prevents responsiveness to interventions to improve self-management and glycaemic control: high diabetes distress constrains energy and reduces motivation to engage meaningfully in self-care tasks [32]. Reducing diabetes distress, however, may allow individuals with diabetes to become more responsive to programmes that target specific management or glycaemic goals. Consequently, programmes for diabetes education and behavioural management may need to accompany diabetes distress interventions to achieve maximum benefits.

### Strategies to consider for inclusion in diabetes distress interventions

Acknowledging the diversity of clinic settings and populations, e.g. Type 1 vs. Type 2 diabetes, those with different treatment regimens, and those with different levels of glycaemic control, complications, etc., we provide below five general strategies to consider when developing structured interventions to reduce diabetes distress. These are based on the protocols of two successful diabetes distress reduction trials [32,33], plus motivational interviewing, empowerment-based training and other evidenced-based intervention programmes [35–38] (Table 2). Illustrations are provided in Table 3. As in any clinical effort, implementation of each needs to be crafted to meet the needs of each individual with diabetes, including their unique sources of distress, management burdens, social context, type of diabetes, etc. Consequently, utilization of all of the steps is not necessary in every case. It should be noted, however, that although the sources of distress of adults with Type 1 and Type 2 diabetes are different (Table 1), the dynamics of intervention remain quite similar in both: that is, the skilful utilization of a focused clinical conversation that includes each of the steps listed below.

#### Assess diabetes distress systematically and regularly

Rather than unsystematically and sporadically inquiring about diabetes distress in individual or group settings, it is helpful to utilize a standardized diabetes distress assessment instrument to all individuals at regular intervals. Diabetes

**Table 2** Five strategies to consider in diabetes distress interventions

Topics	Description
1. Assess diabetes distress systematically and regularly	Self-report surveys: PAID, DDS, T1-DDS
2. Focus on feelings, beliefs, expectations	Content: demonstrate how feelings, beliefs and expectations drive behaviour Process techniques: <ul style="list-style-type: none"> <li>• active exploration,</li> <li>• acknowledge and label feelings,</li> <li>• summarize and reflect frequently,</li> <li>• normalize,</li> <li>• use double reflections</li> </ul>
3. Help gain perspective	Identify distorted assumptions and highlight unrealistic expectations by providing new diabetes-related information
4. Develop a concrete plan	Focus on how feelings are managed so that they can be anticipated; plans should be: <ul style="list-style-type: none"> <li>• focused,</li> <li>• easily achievable,</li> <li>• address small changes,</li> <li>• time-limited</li> </ul>
5. Follow-up	At 2-week intervals: phone, clinic visit.

PAID, Problem Areas in Diabetes; DDS, Diabetes Distress Scale; T1-DDS, Type 1 Diabetes Distress Scale.

distress is often hidden and is rarely mentioned in clinical care such that many individuals experience distress with no overt sign or symptom that might spur inquiry [5]. Hence, consistent and comprehensive assessment can be clinically helpful. Furthermore, sharing the results of the survey can serve as a conversation starter (see Table 3). Diabetes distress scores are 'objective' and they narrow the focus to a specific source to guide the conversation and point to actionable next steps. They also provide a baseline for documenting change following intervention over time. Frequency of diabetes distress assessment should vary by clinical need. Although yearly assessment for all individuals can parallel the frequency of recommended depression screening [3], addressing diabetes distress more frequently around high-risk events, e.g. development of a new complication, during diabetes education or, more importantly, as part of each clinical encounter can be useful.

#### Focus on feelings, beliefs and expectations

The core of many diabetes distress interventions is to foster recognition that 'how you feel affects what you do'; that



**Table 3** Examples for addressing diabetes distress during a clinical conversation

Discuss distress following assessment:	What strikes you as you review your results? Is any of this a surprise to you? Are your scores unexpected? Which of the areas listed are the most important (troubling) to you? Why? You scored high on ... Can you tell me what about ... is distressing you so much?
Acknowledge and label feelings Common feelings that emerge in discussions with distressed adults with Type 1 or Type 2 diabetes: angry, hurt, let down, sad, defeated, ashamed, powerless, guilty, embarrassed	Sounds like you were feeling ... This must have left you feeling ... You must have felt (reacted) ... Have you been feeling ... often or at other times? When have you been feeling ...? How would you describe how you felt? What other feelings occurred? Have you ever felt this way before around your diabetes? Where do you think these feelings come from? Why do you think these feelings are happening now? (For those who rarely use emotion words or who seem hesitant to verbalize, alternative examples can be helpful, e.g. 'Some people tell us that they feel ... when this happens. How have you felt?')
Summarize and reflect: include both the content of the statement and the underlying feeling	'=It seems to me that you are saying that ..., and that you felt ... Please correct me, but are you saying that ... and that you felt ... Just so that I understand, ... Could you tell me more about this so that I can better understand what happened and how you felt?
Normalize	Many people I work with that have diabetes feel exactly the same way This is a typical reaction to when you start trying to change things Of course you feel this way, anyone who is dealing with this 24 hours/day, 7 days/week would feel the same way It's kind of normal to feel this way under the circumstances Does this surprise you? Is this unexpected? This seems to be a normal reaction to struggling with this Many people with diabetes feel this way; they very much want to improve their diabetes, but they often feel that ...
Use double reflections: include both content and feelings	So on the one hand, you feel that adding insulin will improve your glucose levels and help you to feel better, but on the other hand, you worry about the side effects of insulin (weight gain), discomfort taking injections, and a feeling that maybe you failed to take care of yourself as well as you should have So on the one hand, you feel that switching from an insulin pen to a pump might help you to control your sugars better, but on the other hand, you dislike the idea of having an electronic gadget attached to you and worry about how it will affect what clothes you can wear So on the one hand, you really would like to improve your diet (diabetes, etc.), but on the other hand, you are afraid that the programme won't work for you; you are too overwhelmed with things to make it work; (or) you feel that you just won't be able to do it; (or) you fear that you might fail again, etc.
Help the person gain a new perspective:	You seem to be very worried and scared about getting a complication. What worries you the most? Do you know what the actual risks are of getting this complication? How much do you think you need to lower your HbA <sub>1c</sub> to make a difference? Do you have to have an HbA <sub>1c</sub> of 6.5%? How 'perfect do you think you should be to be?' You keep criticizing yourself for how you are managing your diabetes. But although you struggle with your weight, you exercise a lot, take your medications regularly, and check your blood glucose often – so there a bunch of things that you are doing very well
Develop a plan: (what might they feel and how will they manage how they feel?)	How do you think you will feel when you reach for your walking shoes? What will you do when you find yourself feeling like you really don't want to go for a walk? What will it be like for you when you test your blood glucose each morning and see a high number – how will you feel, what will you do? You tend to get really scared when your blood glucose is at 150 and the arrow is heading down. Then you tend to over-react by eating too much. What can you do when you get this scared so that you don't over-react?

feelings, beliefs and expectations about diabetes drive diabetes management behaviour [2]. If you feel hopeless about your ability to manage your diet and you do not expect a weight loss programme to be helpful because you have 'failed' several in the past, the chances are good that not much energy will be devoted to diet management and a

willingness to participate in yet another weight loss programme. Consequently, diabetes distress interventions should include content and experiences to help adults with diabetes recognize and label those feelings, beliefs and expectations associated with their diabetes, thus, making covert experiences overt and subjecting them to examination,

re-evaluation and transformation. To achieve these ends, consider the following clinical tools, illustrated in Table 3 [39].

**Active exploration.** The primary vehicle of change in diabetes distress intervention is the person-centred conversation itself [39]. Most clinicians are excellent talkers and fixers: we spend a great deal of time providing people with diabetes with information and guidance, and studies have shown that in clinical encounters clinicians tend to interrupt people between 11 and 22 s after they begin talking [40–42]. By contrast, addressing diabetes distress requires a more balanced conversation so that an environment can be created to facilitate the expression, labelling and exploration of their distress in ways not necessarily considered previously. This requires a shift from usual clinician activity of information deliverer and problem-solver to active explorer and clarifier, thus creating a more person-centred and person-directed conversation that enhances this process [38]. Changes in clinician behaviour may include talking far less, facing the person with diabetes directly, turning away from computer screens and charts, maintaining good eye contact, and following some of the suggestions listed below through active listening.

**Acknowledge and label feelings.** Many individuals with diabetes pay little attention to their emotional life and some do not have a vocabulary to describe what they feel. Others feel many things at the same time and are unable to clarify and focus on specific emotional experiences. Still others are aware of their feelings but are overwhelmed by their intensity. Providing labels to feelings and bringing feelings into the conversation slowly and systematically, enables them to be recognized and attended to (Table 3). Each simple comment identifies the feeling and provides it with a name so that it can be attended to overtly.

**Summarize and reflect.** An effective way to maintain the focus on affect is to summarize and reflect back the content of individual statements and conclusions. Doing so allows the person to hear what they have just said from another person, making it more objective and open to reconsideration. It also helps them to hear it as a direct and succinct statement, excluding confusing or distracting thoughts and experiences. Likewise, it tells the person that they have been heard accurately, which provides direct support.

**Normalize.** Many people with diabetes feel alone and isolated. Normalizing can be extremely powerful because it enables those with diabetes to recognize that what they are experiencing is to be expected under the circumstances. One major benefit of addressing diabetes distress in group settings is that others can share similar emotional experiences, helping individuals recognize that their feelings are not unusual, and that they are an understandable reaction to diabetes-related events.

**Use double reflections.** Although it is common for people with diabetes to identify the many reasons why it might, for example, be helpful to check their blood glucose frequently, they often are unaware of the very good reasons they have for not testing frequently, e.g. it reminds them that they have diabetes, they do not want to see another high glucose level, etc. The push and pull of conflicting motivations, many of which may be unrecognized, often lead to diabetes distress and behavioural paralysis [37]. An important element of motivational interviewing suggests that efforts to expose and label both sides of the ambivalence can be helpful because they clarify and crystalize the emotional dilemma. They also emphasize the importance of attending to feelings, beliefs and expectations because they tend to drive management challenges. Double reflections are simple summaries that use ‘on the one hand you feel that – but on the other hand you feel that’ statements (see Table 3).

#### **Help the person gain a new perspective**

People experiencing diabetes distress often feel powerless and overwhelmed. They can be highly self-critical and unable to recognize that they have been successful in some areas of management. Furthermore, their criteria for ‘success’ may be distorted or unrealistic. Carefully identifying and examining these criteria can help enhance perspective and re-focus energies into areas that warrant further attention. For example, providing recent information documenting the relative risk of complications and showing that even small reductions in HbA<sub>1c</sub> can lead to substantive reductions in future risk can provide context to management efforts. Doing so often relieves some of the gloom and doom that people feel. Furthermore, a recognition that at least some management successes have been achieved, an awareness that they do not have to be ‘perfect’, and an effort to support more realistic goals based on where the true risks lie help recalibrate perspectives about what is really important. Group discussions among individuals with diabetes about these topics can be particularly helpful by highlighting common worries, misperceptions and inaccurate assumptions, but such discussions can be equally effective within the intimacy of individual encounters.

#### **Develop a plan**

Although in most cases an effective clinical conversation may be all that is necessary, in some cases developing an action plan regarding how to deal with diabetes distress and its impact on management can be helpful. For example, if blaming oneself about how poorly blood glucose levels are being managed leads to high diabetes distress and inaction, then an action plan about the specific sources of distress might be in order. Importantly, the goal is not to change how one feels (as far as we know, there are no internal switches that automatically enable people to feel differently), but rather to address changes in how feelings are managed and attended to [43,44]. For example, a person with diabetes

may report that they find themselves engaging in self-blame after observing a high fasting glucose level. Helping the individual to recognize and expect this feeling to occur when next they observe a high blood glucose reading provides a level of personal control that says: 'I know myself; I know how I will probably feel when I see that blood glucose reading; but I can choose how I will react to it' [11].

#### Follow-up

Although diabetes distress is sensitive to intervention, like most clinical efforts it requires planned, systematic and consistent follow-up. Depending upon source and intensity of distress, and other personal and social contextual factors, we recommend planned follow-up contact within 2 weeks of the initial distress-related encounter. A follow-up through phone or in-person meeting continues the discussion and the interval allows the person with diabetes to uncover previously unrecognized issues. For example, an adult with Type 2 diabetes was complaining initially about how distressed she was because she did not have time to exercise because of work and family demands. At follow-up, 2 weeks later, she reported that she realized that there was another reason that she did not exercise – she felt guilty that she would be taking time away from her busy family. Hence, addressing diabetes distress is not an event: it is an ongoing process that needs to be continued over time.

### Options for where in the care process a diabetes distress intervention might be considered

We have found that best results are achieved when diabetes distress is targeted directly for intervention, rather than indirectly through programmes of education or lifestyle change [32,33]. Although diabetes distress in most cases should, in our view, be attended to in most or all clinical encounters [6], there are occasions during which attention to diabetes distress may provide particularly added value. Four non-exhaustive, non-mutually exclusive strategies are provided below as examples to help guide where in the care process it makes most sense to address diabetes distress in a particular clinical setting.

First are programmes for individuals who are currently experiencing significantly high levels of diabetes distress. Small-group programmes of 6–12 people can be particularly effective when well-structured. A one-half to full-day workshop or a few 2-h meetings also can be effective in dramatically reducing diabetes distress, as well as being cost effective [32]. Group formats are particularly helpful because they allow people to share experiences, thus normalizing and clarifying personal reactions. They also help enhance emotion management skills, such as reducing over-reactions and becoming aware of tendencies toward self-blame, as participants share the ways in which they react to stressful diabetes experiences [45]. For best effects, staff

should have some group process experience and be comfortable dealing with the emotional content of the programme [39]. Targeting diabetes distress in a specialized way for highly distressed individuals can lead to dramatic reductions in diabetes distress and substantive improvements in quality of life [1].

Second, a focus on diabetes distress when critical diabetes events occur may be particularly helpful. These events may include an increase in medication dose or a transition to insulin or other injectables or devices, the emergence or exacerbation of a complication, the period following a severe hypoglycaemic event, or a change in diabetes provider. These are times when both rational and irrational fears may increase, self-evaluations may become distorted by self-blame and fault, and worries about the future may abound. Helping an individual identify and consider their emotional reactions to these kinds of events can provide perspective and lead to a more realistic, modulated and adaptive emotional reaction.

A third strategy is to integrate information about diabetes distress into routine diabetes education seamlessly, both for newly diagnosed individuals and for those receiving a diabetes update or instructions for use of a new device or medication. This could include discussions about how a person might feel when taking certain medications, fears about the accuracy and reliability of a new device, fears about complications, worries about access to health care and covering the cost of medications. Diabetes-related events often signal the progression of diabetes, which can be frightening and demoralizing. Including an emotional component to traditional educational content serves many functions: it normalizes the experience, it enables overt discussion of often covert concerns, and it prevents or reduces future negative experiences by helping individuals anticipate them beforehand, i.e. prevention. Furthermore, doing so expands the therapeutic contract that clinicians have with individuals to include the emotional side of diabetes.

Fourth, and perhaps most importantly, are strategies that integrate discussion about the emotional side of diabetes into all clinical encounters. These can be focused questions about other life stresses or about specific diabetes-related stressors. For example, a clinician might ask: 'How are you feeling about your diabetes?', 'What about your diabetes is most distressing for you now?', 'How have things been going at home, work, etc.?' These kinds of questions need not lead to open-ended, time-consuming discussions; instead, they can help gather information about broader life context and specific diabetes concerns that may impact management and quality of life. They also allow for a more complete continuity of care experience because they provide information about a person's social context that can be addressed during a later visit.

These four strategies simply highlight options to consider as more attention is devoted to the emotional side of diabetes



in clinical practice. We suggest that clinic staff address diabetes distress systematically and comprehensively, rather than on a periodic, person-by-person basis. There is no magic formula in this regard: careful planning taking unique clinic culture, staffing, size and characteristics of the panel into account is probably the best strategy, for it customizes the programme to individual settings and enhances its maintenance over time.

## Conclusions

Although emotions, like diabetes distress, are complex and subjective, they can have a powerful impact on quality of life, disease management and ability/willingness to respond to other diabetes interventions. Diabetes distress is ubiquitous, yet it has been shown to be highly malleable and responsive to intervention. For the most part, distress interventions typically do not require the expertise of a mental health professional, which can be costly and, in most cases, unavailable. With planning they can be incorporated into regular diabetes care by well-trained, sensitive diabetes clinicians. Unfortunately, few clinical settings regularly assess diabetes distress, have prioritized attention to diabetes distress, or have clinicians willing to address diabetes distress as part of comprehensive care. Hopefully, this brief guide will accelerate interest in applying what we know about diabetes distress into the real world of clinical care.

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## Competing interests

None declared.

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