

# Targeting Diabetes Distress: The Missing Piece of the Successful Type 1 Diabetes Management Puzzle

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Type 1 diabetes remains an incurable lifelong condition. It is also a disorder that impinges relentlessly, and often unpredictably, on patients' lives, every hour of every day. Insulin requirements and glucose profiles may vary on a day-to-day basis depending on many factors. Therefore, type 1 diabetes therapy must be reviewed and adjusted frequently to achieve and maintain acceptable long-term glucose control.

Given the complexity of the condition, it is not surprising that living and coping with type 1 diabetes require patients' lifelong commitment and personal responsibility for health and behaviors. Yet, despite the best of intentions and notwithstanding advances in diabetes treatments and the generally high quality of diabetes care, the majority of patients with type 1 diabetes are not reaching glycemic targets (A1C < 7% based on the Diabetes Control and Complications Trial [DCCT] of type 1 diabetes).<sup>1,2</sup> In the DCCT, 44.3% of intensively treated patients and only 4.3% of those in the conventional treatment group had a mean A1C value  $\leq$  7%.<sup>1</sup> Calvert et al.<sup>2</sup> reported that the median proportion of people with type 1 diabetes achieving an A1C of  $\leq$  7.5% in the United Kingdom was 25.8% (interquartile range 20.0–32.5%).

Although flexible insulin regimens offer patients a greater chance of meeting treatment targets, these regimens also place significantly more demands on patients. Importantly, many adults with type 1 diabetes experience psychological difficulties associated with their disease<sup>3,4</sup> that often are unrecognized, unaddressed, or mismanaged

and that hinder patients from better adhering to multiple self-care tasks and achieving adequate glucose control.<sup>5,6</sup> The clinical importance of addressing psychological distress related to type 1 diabetes with its consequences as a serious health issue is highlighted by the recognition that type 1 diabetes is a contributing factor to both depression and distress in the majority of adults with the disease.<sup>6</sup>

Practical recommendations for addressing and mitigating elevated type 1 diabetes–related distress in adult patients are scarce.<sup>7–10</sup> This article aims to increase awareness and understanding of type 1 diabetes–related distress and to assist diabetes health care professionals by proposing therapies to prevent and mitigate it. The proposed recommendations and caveats are based on relevant evidence, including existing guidelines for type 1 diabetes management, previous reports, and the authors' professional experience and personal insight. The ultimate goal is to optimize patient outcomes and stimulate further exploration of the best ways to practically apply the proposed concepts to improve type 1 diabetes care.

## Recognition of Type 1 Diabetes–Related Distress

### Depression versus type 1 diabetes–related distress

The term “depressive disorders” refers to a group of several specified and unspecified depressive disorders of differing duration, timing, and presumed etiology, diagnosed using specific criteria from the *Diagnostic and Statistical Manual of Mental*

*Disorders.*<sup>11</sup> The common feature of all of these disorders is the presence of sad, empty, or irritable mood accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function and that are present for at least 2 weeks.<sup>11</sup>

Previous studies have indicated that the prevalence of elevated depressive symptoms is considerably higher in adults with type 1 diabetes than in the nondiabetic population,<sup>12</sup> and regular screening for depression has been recommended.<sup>13–15</sup> More recently, evidence has emerged to suggest that “diabetes distress,” involving several states related to coping with diabetes, is often mistaken for depression<sup>6,8–10,16,17</sup> because the symptoms can sometimes be identical and confusing. Of great importance is a study by van Bastelaar et al.<sup>17</sup> demonstrating that diabetes distress mediated the relationship between depression and glycemic control in type 1 diabetes. In this study, patients depressed and distressed by type 1 diabetes had poorer glycemic control than those not depressed and distressed, whereas depressed patients without elevated diabetes distress did not

show an increased risk of poorer glycemic control.<sup>17</sup> Fisher et al.<sup>16</sup> further showed that only diabetes distress—and not depressive symptoms—was related to glycemic control in people with type 2 diabetes cross-sectionally and over time.

It is important to note that diabetes distress and depressive symptomatology are often highly correlated among individuals with type 1 diabetes.<sup>18</sup> Type 1 diabetes-related distress is commonly associated with a variety of cognitive, behavioral, and biological symptoms that are often similar to those caused by other disorders. In addition, psychological difficulties related to type 1 diabetes are often masked, mostly as denial, unexplained sadness, or with few or no objective clinical signs present. Table 1 differentiates the differences in signs and symptoms associated with depressive disorders<sup>19</sup> and type 1 diabetes-related distress in adults.

Differentiating depression from type 1 diabetes-related distress has important clinical and therapeutic implications. Whereas treatment of depression is directed at relieving the underlying cause and correcting neurotransmitter abnormalities (with or

without the use of antidepressants), isolated diabetes distress may require different treatment approaches<sup>9</sup> as described further below.

**Etiology of type 1 diabetes-related distress**

Unlike depressive disorders, type 1 diabetes-related distress can be triggered and explained by certain causal factors linked to type 1 diabetes (Figure 1). These factors include emotional burden and nonpsychiatric emotional reactions to the onset, course, management, and complications of type 1 diabetes. The fear of hypoglycemia<sup>4,20</sup> and worry about chronic diabetes complications<sup>21–23</sup> pose additional threats to well-being. Unlike other long-term conditions, type 1 diabetes can also acutely affect patients' mood, thoughts, feelings, behavior, and well-being through alterations in circulating glucose levels, which may vary and change rapidly throughout the day within a period of hours or even minutes.

Importantly, type 1 diabetes-related distress can be modified by the external environment, including society, families, health care services, and peer support groups. However,

**Table 1. Differences in Signs and Symptoms Associated With Depressive Disorders and Type 1 Diabetes-Related Distress in Adults<sup>19</sup>**

Depressive Disorders (Symptom Duration of at Least 2 Weeks With Symptoms Occurring Daily)	Type 1 Diabetes-Related Distress
Depressed and/or irritable mood most of the day	Unexplained sadness or irritability; changes in mood
Markedly diminished interest or pleasure (anhedonia)	Anxiety; fear; anger; frustration; denial
Significant weight loss or weight gain (> 5% body weight within 1 month) or decreased or increased appetite (overeating)	Possible changes in body weight; appetite disturbances
Insomnia or hypersomnia	A variety of sleep disturbances
Psychomotor agitation or retardation	Impaired motivation for self-care
Fatigue or loss of energy	Fatigue or loss of energy
Diminished ability to think or concentrate; indecisiveness	Concentration difficulties
Feelings of hopelessness/worthlessness or inappropriate guilt; low self-esteem	Feelings of helplessness/loneliness
Recurrent thoughts of death or suicidal/homicidal ideation	Intentional isolation; social awkwardness or withdrawal; interpersonal conflicts
Depressive qualities conveyed during the interaction with the interviewer	High-risk health behavior

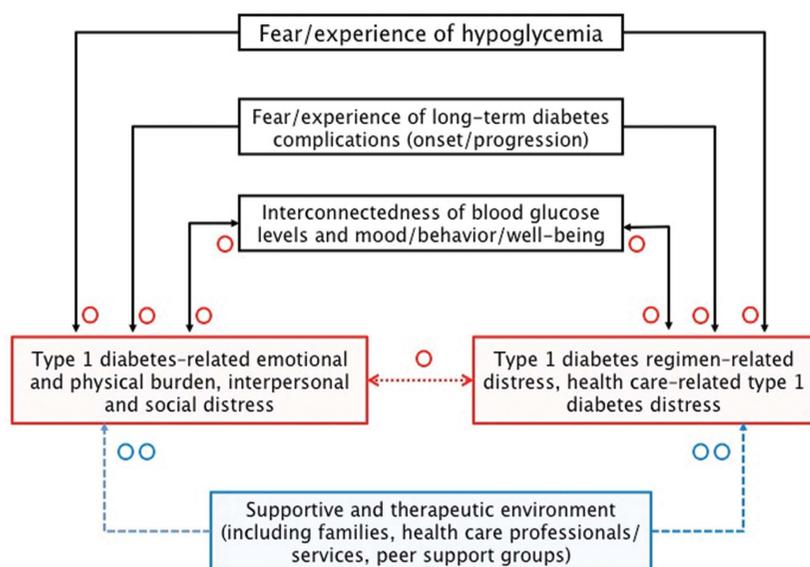


Figure 1. Factors causally linked to type 1 diabetes-related distress.

if left unrecognized or unaddressed, the elevated distress may lead to a vicious cycle of misunderstanding and accelerated frustration, with an adverse impact on glycemic control.<sup>5</sup>

It is important to point out that type 1 diabetes-related distress is a natural part of living and coping with type 1 diabetes, and, as such, it develops and progresses over time. Given that many adults with type 1 diabetes have been diagnosed since childhood, symptoms may develop with the compounded burden of years—or even decades—of disease management. Therefore, both diabetes duration and age at diagnosis may play a role in selecting appropriate therapies to target distress.<sup>7,10</sup>

Early recognition of the symptoms and identifying factors that trigger or worsen type 1 diabetes-related distress are crucial to effective treatment. Therefore, regular screening of both depression and type 1 diabetes-related distress should be more routinely incorporated into clinical care.

#### Screening for type 1 diabetes-related distress

To date, there is no single, objective test to confirm the presence and determine the character and severity of type 1 diabetes-related distress. During consultations, patients often tend not to talk much about experi-

encing feelings that may be very close to depression.<sup>8</sup> Furthermore, clinicians often do not ask for symptoms related to psychosocial distress and, rather, tend to focus on objective health indicators such as glycemic control and risk of chronic complications.<sup>24</sup> To avoid uncertainty, clinicians may need to assess the level and type of type 1 diabetes-related distress on the basis of both structured clinical interviews and subjective self-report diabetes distress questionnaires in concert with their sound clinical judgment.

The contemporary tools used for screening for diabetes distress are based on patient assessment questions to identify and rate specific items within the predetermined diabetes distress-related domains, reflecting the degree to which the item is perceived as currently problematic. Although a number of self-report questionnaires have been developed to screen for diabetes distress, only a few have been tested in adults with type 1 diabetes.<sup>25–29</sup>

Of importance, similar areas of diabetes distress have been reported in previous studies that included adults with type 1 diabetes.<sup>28,29</sup> In 1995, Polonsky et al.<sup>26</sup> developed the Problem Areas in Diabetes (PAID) scale as a screening measure of emotional responses to diabetes. The domains identified within the PAID

included factors labeled as “negative emotions,” “treatment problems,” “food-related problems,” and “lack of social support.”<sup>28</sup>

In 2005, Polonsky et al.<sup>29</sup> addressed some of the limitations of the PAID and developed the Diabetes Distress Scale (DDS17), a 17-item self-report measure of overall diabetes distress and four distinct dimensions of distress experienced during the past month. The DDS17 uses a Likert scale with each item scored from 1 (“not a problem”) to 6 (“a very serious problem”).<sup>29,30</sup> The items are divided into the following four subscales created a priori based on focus group discussions: emotional burden, physician-related distress, regimen-related distress, and diabetes-related interpersonal distress.<sup>29,30</sup>

Although the DDS17 has been used mainly in the United States, a recent large cross-sectional survey of 2,419 European adults with type 1 diabetes showed that the DDS17 is also a valid and clinically useful tool in a European setting and for people with type 1 diabetes.<sup>4</sup> The DDS17 yields a total score plus four subscale scores, each addressing a different kind of distress.<sup>30</sup> In people with type 2 diabetes, a mean item score of 3 or higher (moderate distress) suggests a level of distress worthy of clinical attention.<sup>30,31</sup> In type 1 diabetes, the co-varying relationships between DDS17 and outcomes do not suggest distinct cut points or a threshold DDS17 score for clinically relevant distress.<sup>4</sup>

Findings by Tanenbaum and Gonzalez<sup>6</sup> provided strong evidence that type 1 diabetes-related distress can influence evaluation of clinical depression because of potential symptom overlap. Therefore, further improvement of conceptualization and measurement of type 1 diabetes-related distress is needed to distinguish between symptoms caused by illness burden and those indicating a psychiatric disorder.<sup>6</sup> The dual insights and experiences of patients who are also health care professionals could convey highly useful, evidence-based information to both improve existing screening

**Table 2. Proposed Model of Type 1 Diabetes–Related Distress Management Integrated Within the Multidisciplinary Diabetes Care Team**

Target Area	Specific Task	Care Setting	Potential Barriers
Regular screening for depression and type 1 diabetes–related distress	Structured clinical interviews and subjective self-report questionnaires	Diabetes clinics or a pre-visit setting	Lack of resources or personnel
Type 1 diabetes–related emotional and physical burden	Coping strategies module introduced in a diabetes educator–led education class and refresher courses; follow-up care by diabetes-knowledgeable psychologists; psychological treatments integrated with other diabetes support interventions	Diabetes clinics, mental health professional settings, and diabetes support groups	Time pressures of clinical care, a need for specially educated and trained diabetes care teams, and a lack of psychologists trained in diabetes
Type 1 diabetes–related interpersonal and social distress	Promotion of health behaviors and treatment of psychological problems; increasing public awareness of type 1 diabetes	Diabetes clinics, mental health professional settings, and public and community settings	Lack of psychologists trained in diabetes, lack of resources or personnel, and an unresponsive society
Type 1 diabetes regimen–related distress	Self-management interventions delivered by diabetes educators, diabetes specialist nurses, dietitians, or diabetologists	Diabetes clinic and diabetes support groups	Unintentional nonadherence because of communication failure
Health care–related type 1 diabetes distress	Provision of good clinical care; increase in clinical awareness and understanding of type 1 diabetes–related distress; development of a new model of integrated diabetes care	Primary care and specialist services	Lack of resources or personnel; unwilling, unaware, or unresponsive providers; ill-advised interventions; a fragmented model of diabetes care
All areas of type 1 diabetes–related distress	Follow-up counseling on the use of coping strategies for type 1 diabetes; increasing public awareness of type 1 diabetes; promotion of healthy behaviors	Over the phone	Lack of resources or personnel; need for specially educated and trained diabetes care teams; nonadherence because of communication failure

tools and guide comprehensive treatment approaches.

### Management of Type 1 Diabetes–Related Distress

Type 1 diabetes management is a challenge for both patients and clinicians. With the help of the developed diabetes distress screening tools, we should now be able to identify patients experiencing high levels of type 1 diabetes–related distress and select appropriate treatment approaches.

An important bidirectional link between type 1 diabetes–related distress and glycemic control<sup>5,6</sup>

highlights the role and importance of diabetes specialists in the management of type 1 diabetes–related distress. Management of such distress should ideally be approached on a case management basis using a multidisciplinary diabetes care team<sup>32</sup> that can include endocrinologists, registered nurses, nurse practitioners, physician assistants, certified diabetes educators, dietitians, pharmacists, and diabetes-knowledgeable psychologists. A comprehensive management plan allocating specific tasks and settings (Table 2) should be evaluated and deployed to meet patients'

specific needs. Incorporating type 1 diabetes–related distress assessment into regular diabetes follow-up visits rather than into annual screenings could enable clinicians to identify and respond to its components at an earlier stage.

### Target areas and treatment approaches

Given the multiple components and types of type 1 diabetes–related distress, a multidisciplinary treatment approach is needed to address the complexities of the issue. Specifically, the following four areas of distress (modified from Polonsky

et al.'s DDS17 subscales<sup>29</sup>) should be targeted: 1) type 1 diabetes–related emotional and physical burden, 2) type 1 diabetes–related interpersonal and social distress, 3) type 1 diabetes regimen–related distress, and 4) health care–related type 1 diabetes distress.

**Type 1 diabetes–related emotional burden.** This refers to nonpsychiatric emotional reactions to the onset and course of type 1 diabetes, including subjectively perceived self-care demands and the threat of complications.<sup>21–23</sup> During the course of type 1 diabetes, the burden may extend to physical distress in response to progression of chronic complications and disease-associated functional impairment. Given the close interrelationship between type 1 diabetes–related distress and type 1 diabetes self-management,<sup>5</sup> the elevated emotional burden may trigger a vicious cycle of deterioration in glycemic control and further worsening of distress.<sup>6</sup>

Because emotional burden may often be underdiagnosed even in young adults with reasonably well-controlled type 1 diabetes,<sup>10</sup> it should be evaluated regularly as part of ongoing diabetes care. Patients experiencing high levels of type 1 diabetes–related emotional distress can be referred to a diabetes-knowledgeable mental health professional for follow-up care.

**Type 1 diabetes–related interpersonal and social distress.** Interpersonal distress may arise as a result of unsupportive interpersonal relationships<sup>33</sup> or may be triggered by an adverse impact of type 1 diabetes on the pursuit of interpersonal goals.<sup>22,23</sup> In a similar way, social distress may arise from diabetes stigma, social awkwardness, and isolation or from patients' inability to fully participate in social activities.<sup>10,34</sup> Importantly, recent findings by Balfe et al.<sup>10</sup> suggest that stigma not only is a serious problem in itself, but also can discourage young adults from seeking help for type 1 diabetes–related distress. Identifying issues related to type 1 diabetes–related social distress can enable clinicians to tailor therapy based on patients' individual needs and decide on the next best step in the complex treatment of type 1 diabetes.

**Type 1 diabetes regimen–related distress.** This can arise from the continual self-care demands related to diabetes self-management. Previous studies have identified several factors associated with regimen-related distress, including less frequent self-monitoring of blood glucose, poorer adherence to meal planning, less exercise,<sup>29</sup> and financial strain from diabetes-related expenses.<sup>6</sup> Many adults with type 1 diabetes also report concerns, distress, and frustration about injecting insulin in front of other people.<sup>10</sup> Similarly, those who use a continuous subcutaneous insulin infusion regimen point to anxiety about wearing an insulin pump.<sup>6</sup>

Regimen-related distress often intermingles with other types of type 1 diabetes–related distress such as emotional burden and social distress,<sup>10,34</sup> which places considerable demands on individuals with type 1 diabetes. The art of coping with type 1 diabetes develops in time and is dependent on patients' full acceptance of type 1 diabetes, which is usually a slow and gradual process.<sup>35</sup>

During the course of type 1 diabetes, patients may experience diabetes denial, which may impede their adherence to self-care tasks. Even a partial continual denial of type 1 diabetes may lead to serious health and social consequences, while preventing patients from fully understanding diabetes and applying their knowledge of health management and diabetes treatment to everyday life. Moreover, denial can trigger other type 1 diabetes–related psychological issues. Developing an early understanding that type 1 diabetes might be demanding, exhausting, intrusive, frustrating, discouraging, or even exasperating, and also that it may affect friends and family, can help people with the disease prepare to eventually face such situations in the future and develop effective coping strategies in a timely manner.

Elevated type 1 diabetes regimen–related distress can be identified by clinicians or diabetes educators during follow-up visits. The strategy of developing and deploying effective coping mechanisms can be intro-

duced in a diabetes educator–led education class. Novel interventions that integrate psychological treatments (e.g., cognitive behavior therapy) into the diabetes care plan can lead to overall self-management improvements in adults with poorly controlled type 1 diabetes.<sup>36</sup>

**Health care–related type 1 diabetes distress.** This may be the result of unresponsive health care providers or struggles with the health care system.<sup>29</sup> Type 1 diabetes–related distress is an underappreciated part of living and coping with type 1 diabetes, and it needs to be perceived as such, rather than ignored. Addressing psychological difficulties related to type 1 diabetes requires clinical awareness and understanding of this type of distress. Clinicians should feel comfortable talking about these psychological issues and intentionally bring them up during regular follow-up visits.<sup>8</sup>

However, many clinicians find themselves uncertain about how to positively approach patients with type 1 diabetes–related distress.<sup>10</sup> Moreover, psychological issues often remain overshadowed by time-consuming management of other challenges and barriers to glycemic control in outpatient settings.<sup>24</sup> Although it may be impossible to cover all components of care within the clinician's 15- to 30-minute contact with a patient, an individualized therapeutic approach based on open conversation can be used during the encounter to convey understanding of the patient's problems related to type 1 diabetes.

A more thorough assessment of diabetes-related distress can be offered by the diabetes education team to help patients address their feelings and move toward a more balanced approach to living with diabetes. Physicians, nurses, and other health care professionals who patients can trust should serve as attentive and empathic listeners who can identify patients who need to be provided with additional opportunities to explore their feelings.<sup>7–10,33</sup> In addition, any mitigation of emotional burden initiated by the clinician can reduce the health care–related distress at the same time.

## Future Perspectives

Diabetes distress is common and has important clinical implications for the health and well-being of adults with type 1 diabetes. Evaluation of and intervention in type 1 diabetes-related distress should be more routinely incorporated into clinical care. The focus of care should also be on early diagnosis and treatment of patients with type 1 diabetes and comorbid depression.

As described above, one effective way of targeting type 1 diabetes-related distress requires clinicians to develop a strong relationship and active collaboration with patients to gauge the severity of their distress and identify barriers that affect their self-care. Effective mitigation of elevated type 1 diabetes-related distress may be accomplished by providing education and counseling about issues such as diabetes denial and coping with the effects of type 1 diabetes on relationships, as well as by providing professionally facilitated peer support groups. A combination of ongoing diabetes self-management education in line with the standards of diabetes care and education<sup>37</sup> and the addition of a type 1 diabetes-specific distress component suitably integrated within the multidisciplinary diabetes care team is needed for optimal type 1 diabetes management.

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