



**Received:** 23-09-2025 **Accepted:** 03-11-2025

## International Journal of Advanced Multidisciplinary Research and Studies

ISSN: 2583-049X

### The Burden of Diabetes Distress Among Persons Living with Diabetes Mellitus

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#### Abstract

Diabetes distress, the emotional and psychological burden associated with living with and managing diabetes, is usually attributed to the demands of living with the disease. Additional factors bordering on the attitude and behaviour of healthcare providers, as well as the social context in which affected persons live, also contribute to experienced diabetes-related distress. It is a significant issue that can impact both the mental well-being and the physical health of affected persons, and ultimately treatment adherence and disease control. This narrative review explored existing evidence on the reported burden of diabetes distress among persons living with diabetes mellitus vis-a-vis its prevalence and severity, as well as contributing factors and impact on psychological well-being and quality of life. Extensive literature search of relevant database was conducted. Findings revealed that diabetes distress is a common

situation affecting a significant portion of persons living with diabetes. It is associated with poorer glycemic control and overall health outcomes. Socio-demographic and disease-related factors, and psychological comorbidities were reported to be frequently associated with higher levels of diabetes distress. Elevated diabetes distress is a barrier to diabetes management and optimal self-care, often leading to poorer treatment outcomes. Empowering affected persons with diabetes self-management skills was reported to significantly reduce emotional and regimen distress, with consequent significant improvement in treatment outcomes and health-related quality of life. The entire healthcare team should regularly explore and cater to the diabetes distressrelated needs of persons living with the various types of diabetes mellitus in order to optimize their well-being and treatment outcomes.

Keywords: Diabetes Distress, Diabetes Mellitus, Burden, Diabetes Self-Management Support

#### Introduction

Diabetes mellitus is a global public health crisis, affecting an estimated 537 million adults worldwide, with projections indicating a rise to 783 million by 2045 (IDF, 2021) [25]. The rigorous nature of diabetes management, which requires daily self-care activities like medication use adherence, blood glucose monitoring, dietary adjustments, and physical activity, imposes a significant burden on individuals living with the disease. This burden is not merely physical or financial but also psychological and emotional and can result in a condition known as diabetes distress (DD). It is defined as the significant emotional turmoil, frustration, and worry that stem from the demands of living with and managing diabetes (Dennick, Sturt, & Speight, 2017) [12].

DD refers to the psychological and emotional burden associated with living with and managing diabetes. However, some other parameters bordering on the attitude and behaviour of healthcare providers as well as the social context in which affected persons live have been observed to also contribute to experienced diabetes-related distress. Polonsky *et al* (2005) [33] describe it as a multifaceted construct encompassing the emotional burden of the disease, the challenges of the self-management regimen, the complexities of interpersonal relationships, and the interactions with healthcare providers.

With about half a billion adults currently living with diabetes globally (Cho *et al*, 2018), DD could be of significant epidemiological importance. More than half of adults with diabetes in the United States report experiencing some level of DD (Alexander *et al.*, 2025) [3]. The prevalence is also high in other parts of the world, with a meta-analysis conducted in South Asia reporting a pooled prevalence of 44% (Kamrul-Hasan *et al.*, 2025) [28]. This emotional burden poses a significant barrier to effective diabetes management and is linked to suboptimal glycemic control, reduced self-care behaviors, lower quality of life, and increased risk of long-term complications (Hagger *et al.*, 2018; Park *et al.*, 2024) [20, 32].

The economic and societal costs of diabetes are quite significant, a large portion of which can be attributed to the management of diabetes-related complications. Given that DD is a major barrier to effective self-management, addressing it is not only a matter of improving individual well-being but also a critical strategy for mitigating the broader public health and economic impact of diabetes (Elmusharaf *et al*, 2025) [13].

This narrative review aimed to synthesize existing evidence on the burden of DD among individuals with diabetes. Specifically, it explored the prevalence and severity of DD, identify key sociodemographic, clinical, and psychological factors that contribute to it, and examine its profound impact on health outcomes and psychological well-being among persons living with the disease. It is expected that the findings will highlight the clinical importance of recognizing, assessing, and managing DD as an integral component of comprehensive diabetes care.

#### Methods

This study is a narrative review of existing literature. A comprehensive literature search was conducted in prominent electronic databases, including PubMed, EMBASE, and Google Scholar, to identify relevant peer-reviewed journal articles, guidelines, and textbooks.

#### Findings and Discussion Prevalence of Diabetes Distress

DD is a pervasive issue among individuals with diabetes, with prevalence rates varying significantly across different populations and geographical regions. Recent data from the Centers for Disease Control and Prevention (CDC), as reported by Alexander *et al* (2025) [3] in their National Health Interview Survey, indicate that more than half of adults with diagnosed diabetes experience some level of diabetes distress. About 6.6% of the adult participants with diabetes reported severe distress, 24.3% reported moderate distress, and 19.9% reported mild distress. These findings underscore the substantial psychological and emotional burden of living with and managing diabetes, suggesting that these aspects of diabetes management are probably not getting the required attention in clinical practice.

A systematic review and meta-analysis focusing on South Asian countries revealed a similarly high, albeit varied, prevalence. The pooled prevalence of diabetes distress among people with type 2 diabetes in this region was 44%. However, there were remarkable differences between countries, with Pakistan reporting the highest prevalence at 85%, followed by India and Bangladesh at 42%, and Sri Lanka at 25% (Kamrul-Hasan et al., 2025) [28]. This variation highlights the influence socioeconomic, and healthcare system differences on the experience of diabetes distress. The South Asia study also provided an analysis of the different domains of distress, revealing that emotional burden was the most prevalent form (60%), followed by regimen-related distress (51%), interpersonal distress (31%), and physician-related distress (17%). The notably high prevalence of emotional and regimen-related distress suggests that the core challenges for individuals in this region lie in the personal emotional management of the disease and the practical burdens of daily self-care.

The burden of diabetes distress also differs by diabetes type

and age. Among adolescents with type 1 diabetes, a particularly vulnerable group navigating the complexities of their condition during a critical developmental stage, approximately one-third experience elevated levels of distress (Sturt et al, 2015 [39]; Hager et al, 2016; Hedge et al., 2023 [21]) often linked to suboptimal glycemic control and reduced self-care. For adults with type 2 diabetes, the prevalence of severe distress has been reported to range widely from 13.4% to 76.2% in various studies, with one study finding a prevalence of 48.6% in an elderly population (Batais et al, 2021 [10]; Kalra et al, 2020 [27]; Alwani et al., 2024 [6]; Alzadbakht et al, 2020). AlOzairi et al (2024) [5] reported a prevalence of rate of 27.8% among people living with Type 1 diabetes in Kuwait. Furthermore, about 25% of young adults with early onset type 2 diabetes also reportedly experience clinically significant distress (Trief et al., 2022)

#### **Diabetes Distress versus Depression**

Related to but distinct from depression, it is a significant issue that can impact both the mental well-being and the physical health of affected persons, and ultimately treatment adherence and disease control (Sturt *et al*, 2015) [39]. It is crucial to distinguish DD from clinical depression. While they can coexist and share symptoms, DD is a reaction specifically to the challenges of managing diabetes, whereas depression is a broader mood disorder (AlOzairi *et al*, 2024; Fisher, Glasgow, & Strycker, 2010) [5, 15]. AlOzairi *et al* (2024) [5], however, demonstrated a strong correlation between DD and depressive symptoms among people with Type 1 diabetes and ssserted that the co-existence of both symptoms is associated to numerous sociodemographic and clinical factors.

The primary distinguishing feature is the source of the distress. Diabetes distress is an emotional reaction specifically to the burden of living with diabetes, the self-management tasks, the fear demanding complications, the social stigma, and the challenges of navigating the healthcare system (Sturt et al, 2015) [39]. In contrast, clinical depression is a pervasive mood disorder that affects all aspects of an individual's life and is not solely tied to their diabetes. This distinction is important because interventions for depression may not effectively alleviate DD, and vice versa. In addition, misdiagnosing diabetes distress as depression can lead to the provision of inappropriate care. Antidepressants might be effective for the treatment of clinical depression but not for diabetes distress with a root cause traceable to the practical and emotional challenges of managing and living with the disease itself. However, interventions designed to address diabetes distress, such as enhancing self-management skills, improving communication with healthcare providers, and building social support, can be highly effective in reducing the emotional burden and improving glycemic control, even in the absence of antidepressant medications (Fisher, Glasgow, & Strycker, 2010) [15].

Diabetes distress has also been reported to have a stronger and more consistent association with glycemic control and self-management behaviors than with depression (Hagger *et al.*, 2018) <sup>[20]</sup>. This corroborates foregoing discussion that, from a clinical perspective, assessing and addressing diabetes distress is an effective pathway to improving overall diabetes treatment outcomes.

#### **Factors Contributing to Diabetes Distress**

The development and severity of diabetes distress are influenced by a confluence of sociodemographic, clinical, and psychological factors. Sociodemographic factors such as being married, illiterate, not working (Unemployed), and living with insufficient income were observed to be significant predictors of DD. Other factors reported in another study as common predictors of higher distress include being unmarried, and living in a rural area, poor glycemic control, longer duration of diabetes, severe hypoglycemia, younger age, being female, and having multiple comorbidities (Ibrahim *et al.*, 2023 <sup>[24]</sup>; Liew *et al.*, 2022 <sup>[29]</sup>; Fisher *et al.*, 2016 <sup>[16]</sup>; Fisher *et al.*, 2015 <sup>[17]</sup>; Batais *et al.*, 2021 <sup>[10]</sup>; Alzadbakht *et al.*, 2020).

Women often reported higher levels of overall DDS, emotional and regimen-related distress but not interpersonal distress. This may be attributable to a combination of factors, including societal roles, differences in coping mechanisms, and potential biases in healthcare interactions. (Ahmed *et al*, 2022; Alexander *et al.*, 2025; Quinn *et al*, 2017) [1,3,35].

The consistent finding of higher levels of distress among those with lower income and education levels also points to the critical role of social determinants of health. Financial constraints can create significant barriers to accessing medications, healthy foods, and good quality healthcare, all of which are major sources of stress and anxiety for individuals managing diabetes.

Clinical factors are also strong predictors of diabetes distress. Poor glycemic control, indicated by HbA1c levels above the normal range, is both a cause and a consequence of diabetes distress. Similarly, a longer duration of the disease (diabetes), the presence of diabetes-related complications, and the experience of severe hypoglycemia are all associated with a greater emotional burden (AlOzairi *et al.*, 2024; Baek *et al.*, 2014) <sup>[5, 9]</sup>. The complexity of the treatment regimen, such as the use of insulin, can also contribute to regimen-related distress (German *et al.*, 2023) <sup>[19]</sup>

Psychological factors are strongly associated with diabetes distress. Co-morbid mental health conditions, such as depression and anxiety, are frequently and strongly associated with higher levels of DD (Ahmed *et al*, 2022 <sup>[1]</sup>; Batais *et al*, 2022; Riise *et al.*, 2025 <sup>[36]</sup>). Research suggests that anxiety may have an even stronger association with DD than depression. An individual's self-perception of their health also matters, as those with fair or poor self-reported health were reported by Alexander *et al* (2025) <sup>[3]</sup> to be more likely to experience significant distress. Morales-Brown *et al* (2024) <sup>[31]</sup> reported that the feeling of not being in control was a major area underpinning experiences of diabetes distress among affected persons.

#### **Impact of Diabetes Distress on Health Outcomes**

Elevated DD is a barrier to optimal self-care and diabetes management, often leading to poorer treatment outcomes (Skinner *et al*, 2020) <sup>[38]</sup>. It has been reported to exert undesirable impact on a wide range of diabetes-related health outcomes. A well-documented impact is on glycemic control, with available evidence demonstrating a significant association between higher levels of DD and elevated HbA1c levels (Fisher *et al.*, 2010; Park *et al.*, 2024; Sendekie *et al.*, 2025) <sup>[15, 32, 37]</sup>. Another study suggests that DD is a stronger predictor of HbA1c than depression,

highlighting its clinical importance in glycemic management (Hagger *et al.*, 2018) <sup>[20]</sup>. The relationship appears to be bidirectional, creating a vicious cycle where poor glycemic control induces or exacerbates distress, and the resulting emotional burden leads to poorer self-care and further deterioration of glycemic control. This cyclical nature underscores the importance of considering DD as a one of the primary targets for improving glycemic outcomes.

Another reported impact is on self-care behaviors. Individuals experiencing high levels of diabetes distress are reportedly more likely to have reduced engagement in self-care activities, such as blood glucose monitoring, healthy eating, physical activity, and adherence to the use of prescribed medication (Ajele *et al.*, 2025) <sup>[2]</sup>. The emotional burden of managing and living with the disease can lead to feelings of being overwhelmed and a sense of futility, both of which can undermine motivation to perform the daily activities of diabetes management.

The impact on quality of life could also be significant. DD has been reported to be consistently associated with a lower health-related quality of life (HR-QoL), affecting emotional well-being, social functioning, and overall life satisfaction (Aliche & Idemudia, 2024; Hoogendoorn et al., 2020) [4, 22]. The constant worry, frustration, and feelings of being overwhelmed can diminish the ability to enjoy daily activities and relationships. This reduction in quality of life can manifest in various ways, ranging from social withdrawal and avoidance of activities that may complicate diabetes management, to a pervasive sense of being defined by the disease. The psychological toll on affected persons can be immense, leading to burnout and a state of persistent emotional exhaustion that further compromises that affect the ability to cope with the demands of managing and living with diabetes.

# Screening and Interventions for Managing Diabetes Distress

Given the high prevalence and significant negative impact of DD, its identification and management are crucial components of comprehensive diabetes care. Clinical guidelines like the American Diabetes Association (ADA) Standards of Care and the European Association for the Study of Diabetes (EASD) guidelines now recommend routine screening for diabetes distress (ADA, 2025; EASD, 2026 [14]). Validated screening tools, such as the 17-item Diabetes Distress Scale (DDS-17) and the 20-item Problem Areas in Diabetes (PAID) scale, are available to facilitate this process in clinical practice (Polonsky *et al.*, 2005; Welch *et al.*, 1997) [33, 42]. The DDS-17 assesses four distinct domains of distress, namely emotional burden, regimenrelated distress, interpersonal distress, and physician-related distress, allowing for a more targeted understanding of an individual's specific challenges. The PAID scale provides a general measure of diabetes-related emotional distress, with a score of 40 or higher indicating a need for further assessment and intervention.

Brief screening tools, such as the two-item DDS-2, have also been developed for use in busy clinical settings to rapidly identify patients who may require a more comprehensive assessment, rather than administering the full tool to each and every diabetes patient (Fisher *et al.*, 2008) <sup>[18]</sup>. The successful integration of these tools into routine care is a critical first step toward addressing the problem.

Once identified, DD can be addressed through a variety of interventions. Diabetes self-management education and support (DSMES) programmes are a cornerstone of DD management (ADA, 2025). Empowering individuals with the diabetes self-management knowledge, skills, and confidence to manage their condition can significantly reduce emotional and regimen-related distress, leading to improved glycemic control and quality of life (Cheng *et al.*, 2021; Misra *et al.*, 2021; Powers *et al.*, 2020) [11, 30, 34].

Psychological interventions are also highly effective. Approaches such as cognitive behavioral therapy (CBT), motivational interviewing, and mindfulness-based interventions have been shown to reduce DD and improve psychological well-being (van Son *et al.*, 2013; Zu *et al.*, 2024; Hu *et al.*, 2025) [41, 43, 23]. For adolescents, interventions based on positive psychology have also shown promise (Jaser *et al.*, 2020) [26].

A collaborative, multidisciplinary approach involving a team of physicians, nurses, diabetes educators, nutritionists, medical social workers, and mental health professionals could be an effective way to address the complex interplay of physical and emotional health in diabetes. This teambased approach allows for the integration of medical management with psychological support, ensuring that the patient's needs are addressed holistically. Effective communication and coordination between multidisciplinary team of professionals are key to providing seamless and effective care that empowers the patient and reduces the sense of care fragmentation and burden that can often accompany living with and managing a chronic illness.

#### **Summary**

DD is common, affecting a significant proportion of persons living with diabetes mellitus. Elevated and untreated DD can leading to a vicious cycle of poorer self-management, suboptimal glycemic control, an increased risk of long-term complications. and poor overall health outcomes. Physicians and the entire healthcare team should regularly explore and cater to the diabetes distress-related needs of persons living with the various types of diabetes mellitus in order to optimize their well-being and treatment outcomes.

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