



## DIABETES DISTRESS: THE UNTOLD HIDDEN STRUGGLE OF LIVING WITH DIABETES MELLITUS

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**ABSTRACT:** *In recent years, the global burden of diabetes distress has increased significantly, imposing mental health issues on patients and the healthcare system. Diabetes-related distress differs from depression as it originates from the mental and emotional burden that comes from the ongoing management of diabetes. Studies have revealed that one in four individuals with type 1 diabetes has increased levels of diabetes distress, and one in five people with type 2 diabetes experiences increased levels of diabetes distress. Patients with diabetes experience psychosocial and emotional problems in response to these lengthy therapies, including worry about complications, fear of hypoglycemia, fatigue regarding poorly controlled blood glucose, worthlessness, the need for support, and access to healthcare. Psychological factors such as diabetes-related emotional distress have been linked with lower compliance to diet, exercise, frequent blood glucose testing, and medication regimens. Patients with a higher level of diabetes-specific emotional distress have been shown to have a lower health-related quality of life. Despite the increased awareness and knowledge of diabetes-related distress, patients with diabetes are not routinely screened during clinic visits. Therefore, nurses must continually observe and assess a patient's physical and emotional response to treatment and identify patterns and trends suggestive of diabetes-related distress.*

**KEYWORDS:** Diabetes distress, Diabetes mellitus, Nursing assessment, Diabetes Distress Scale (DDS).



## INTRODUCTION

### Incidence and Prevalence of Diabetes Mellitus

Diabetes is a global epidemic becoming one of the most significant epidemics of the twenty-first century. Globally, the prevalence of chronic, non-communicable diseases is rising at an alarming rate. In this new global landscape of health and disease, the impact of diabetes is genuinely overwhelming and thus should be a concern for all. Diabetes occurs when the body cannot process and use glucose from the food for cells to use as energy, thus resulting in the build-up of extra glucose in the bloodstream. Diabetes mellitus (DM) is a chronic metabolic disease of chronic hyperglycemia characterized by carbohydrate, protein, and fat metabolism disturbances due to absolute or relative insulin deficiency with dysfunction in organ systems (WHO, 2021). If not adequately managed, DM may significantly diminish the patient's quality of life (QoL) and socioeconomic consequences.

Approximately 537 million people (20–79 years of age) suffer from DM globally, and it is projected that the total number of people who have diabetes may rise to 643 million by 2030 and 783 million people by the year 2045. The developing countries seem to be the worst-hit countries with diabetes mellitus, as statistics show that 3 in 4 adults with diabetes reside in low- and middle-income countries, and almost 1 in 2 (240 million) adults with diabetes are undiagnosed. An estimated 19 million adults live in Africa, which is estimated to increase to 47 million by 2045 (Saeedi et al., 2019). Greater than 1.2 million children and adolescents (0–19 years) live with type 1 diabetes, and approximately diabetes affects 1 in 6 live births (21 million) during pregnancy. Also, 541 million adults are more likely to develop type 2 diabetes (International Diabetes Federation, 2021). In addition, between 2000 and 2016, there was a 5% increase in premature mortality (i.e., before the age of 70) from diabetes. In 2019, diabetes was recognized as the ninth top cause of death, with an estimated 1.5 million deaths. About 48% of all deaths due to diabetes occurred before 70 years (WHO, 2021). The International Diabetes Federation (IDF) (2021) opined that diabetes has caused about 6.7 million deaths.

The nationwide health (Diabetes) survey in Nigeria conducted in 1992 revealed a diabetes mellitus (DM) prevalence of 2.2%. However, according to IDF (2022), the prevalence of DM among adults aged 20–69 years was reported to be 3.7%, amounting to 3,623,500 total cases of adults with Diabetes (IDF, 2022). These prevalence figures reported by the IDF may have grossly under-report the actual burden of DM in Nigeria, given that they may have been derived through extrapolating data from other countries. However, researchers have reported prevalence rates ranging from 2% to 12% across the country in recent years (Gezawa et al., 2015; Uloko et al., 2018). Ogun State has about a 5% prevalence rate of Diabetes (World Diabetes Foundation, 2018).

### Diabetes Mellitus

Diabetes mellitus arises when impaired insulin secretion and variable degrees of peripheral insulin resistance result in hyperglycemia. Individuals' early symptoms may include polydipsia, polyphagia, polyuria, and blurred vision. Diabetes mellitus, if not properly managed, may result in vascular disease, peripheral neuropathy, nephropathy, and predisposition to infection. Diabetes can be diagnosed by estimating a person's plasma glucose. The management of diabetes mellitus is based on the specific type. However, general treatment may include diet therapy, exercise, and medications that help to reduce glucose levels, including insulin, oral



antihyperglycemic, and non-insulin injectable drugs. The various complications of diabetes mellitus can be prevented or delayed via satisfactory glycemic control. Heart condition is the top cause of mortality in diabetes mellitus (Brutsaert, 2022).

## **Types of Diabetes Mellitus**

### **Prediabetes**

In prediabetes, the blood glucose levels are elevated to be assumed normal but not elevated sufficiently to be labeled diabetes. An individual is deemed prediabetes if the outcome of the fasting blood glucose level is between the range of 100 mg/dL (5.6 mmol/L) and 125 mg/dL (6.9 mmol/L) or if the blood glucose level 2 hours after a glucose tolerance test ranges between 140 mg/dL (7.8 mmol/L) and 199 mg/dL (11.0 mmol/L). A person diagnosed with prediabetes has a higher chance of future diabetes and a heart condition. Reducing body weight by 5% to 10% via diet therapy and active exercise can significantly decrease the risk of developing future diabetes (Brutsaert, 2022).

### **Type 1 Diabetes Mellitus**

About 10% of all people with diabetes have type 1 diabetes, resulting from an autoimmune response whereby the body's defence system attacks the cells that produce insulin. This causes the body to produce a very minute quantity of insulin or no insulin. The specific causes of this condition are not yet fully understood, but a combination of genetic and environmental conditions has been queried. Type 1 diabetes is commonly seen among children or young adults. People diagnosed with type 1 diabetes require daily insulin injections to maintain their blood glucose within the appropriate level. Studies are ongoing to decipher the risk factors for type 1 diabetes; however, having a family member with type 1 diabetes increases the risk of others developing the disease. Environmental factors and exposure to viral infections have also been correlated to the risk of developing type 1 diabetes (International Diabetes Federation, 2017; 2021; 2022).

### **Type 2 Diabetes Mellitus**

On the other hand, about 90% of all diabetes cases are Type 2 diabetes, thus making it the commonest type of diabetes. According to International Diabetes Federation, more than 380 million individuals worldwide are diagnosed with type 2 diabetes (IDF, 2017; 2021; 2022). Generally, type 2 diabetes mellitus is characterized by insulin resistance, whereby an individual's body does not fully respond to insulin. Because insulin cannot work correctly, the person's blood glucose levels keep rising, releasing more insulin. For some individuals with type 2 diabetes, this situation exhausts the pancreas, resulting in the body producing less insulin, causing even higher blood sugar levels (hyperglycemia). Though type 2 diabetes is commonly seen in older adults, it is now increasingly seen in children, adolescents, and younger adults due to rising levels of obesity, physical inactivity, and poor diet (IDF, 2021; 2022).

Studies have shown that the core of type 2 diabetes management is a healthy diet, increased physical activity, and healthy body weight (WHO, 2021). Also, oral antidiabetic drugs and insulin are frequently prescribed to help control blood glucose levels. Type 2 diabetes mellitus (T2D) can change life experiences, alter self-esteem, challenge present existence, and increase uncertainty about the future. The lives of individuals diagnosed with type 2 diabetes would



change from the moment they experience the symptoms such as chronic hyperglycaemia, weight loss, skin infections, and lethargy to the diagnosis of the condition. A complete change in daily life routines continues from the demands of more regular healthy lifestyles, adherence to daily medication, and scheduled visits to various healthcare professionals. In other words, a healthy lifestyle and performance of adequate and appropriate self-care behaviours are critical elements of good-quality care for individuals with type 2 diabetes mellitus.

Diabetes Mellitus complications can have a significant impact on the lives of patients as well as health care systems (IDF, 2017; Nouwen et al., 2019; van Puffelen et al., 2020). Physical exercise, a healthy diet, regular foot, medication self-administration, and glucose checks to monitor and detect risk factors and symptoms of these complications have been proven effective in reducing the risk of these micro- and macrovascular complications (Jannoo et al., 2017). For these reasons, medical doctors and nurses should invest much time in self-care and lifestyle changes for patients with type 2 diabetes. Currently, the essence of tailoring the healthcare professionals' support to the specific needs of patients has been emphasised (Aguiar et al., 2017; Nelson et al., 2016).

### **Gestational Diabetes**

Gestational diabetes is a type of diabetes mellitus that occurs only during pregnancy. According to the IDF (2019), about 223 million women (20–79 years old) were living with diabetes. This figure is projected to increase to 343 million by 2045. An estimated 20 million or 16% of live births had some form of hyperglycaemia in pregnancy, and about 84% were due to gestational diabetes. Also, 1 in 6 births was affected by gestational diabetes. The majority of cases of hyperglycaemia in pregnancy were recorded in low- and middle-income countries, where access to maternal care is often limited.

The conditions often have no symptoms, or they may be mild, such as being thirstier than normal or having to urinate more frequently. Gestational diabetes is sometimes related to hormonal changes during pregnancy that make a woman's body less able to utilize insulin. Genes and being overweight may also play a role in the development of gestational diabetes. Maintaining a balanced diet and engaging in regular exercise are part of managing gestational diabetes. If the blood sugar levels are still unstable after beginning a diet and exercise routine or if the blood sugar level is extremely high when first diagnosed, anti-diabetic medications (often metformin or insulin injections) may be prescribed.

### **Economic Impact of Diabetes Mellitus**

Diabetes mellitus has imposed an enormous clinical and economic burden on individuals and society. This economic burden encompasses direct costs due to medical and healthcare services and indirect costs resulting from unproductiveness and disability. Globally, the health care expenditure for patients with diabetes is about 2- to 3-fold higher than that for patients without Diabetes. For instance, the treatment of Diabetes caused at least 966 billion dollars in health expenditure – 9% of total spending on adults (IDF, 2019; 2021).

In Africa, the economic impact of Diabetes is on the rise, and currently, about US\$ 9.5 billion have been spent on Diabetes in Africa (IDF, 2019). However, the costs of Diabetes in many African countries may be underestimated due to the paucity of data on the relative contribution of the cost of diabetes complications. In Nigeria, the annual direct costs of Diabetes is about US\$1.639 billion per year, given its population size and current prevalence rates, with the



estimated monthly direct medical costs for patients with T2DM in Nigeria varying between \$262.22 to \$400.52 per patient (Mapa-Tassou et al., 2019).

### **Diabetes-Related Distress**

In recent years, the global burden of diabetes distress has increased significantly, imposing mental health issues on patients and the healthcare system. Diabetes distress is also known as “diabetes-specific distress” or “diabetes-related distress.” In 1995, a team of psychology professionals from the Joslin Diabetes Center introduced the term “diabetes distress” to describe the negative emotional phenomenon that people with diabetes experience (Skinner et al., 2020). Diabetes distress develops from the continued emotional burdens of worry, anger, frustration, and burnout resulting from the constant intricacies that one must balance to maintain ideal glycaemic control (Owens-Gary et al., 2019). It is an individual emotional reaction to living with diabetes, the burden of persistent day-to-day self-management, and its long-term complications (Fisher et al., 2014; Skinner et al., 2020).

Diabetes-related distress differs from depression as it develops from the mental and emotional burden that comes from the constant management of diabetes. These two diagnoses can occur simultaneously, with approximately 4.5% of people with diabetes screening positive for both. Women, young people with diabetes, and people with lower education and socioeconomic status are at even higher risk of major depressive disorder and diabetes distress (Sweatman et al., 2017). In addition to diabetes distress, a person with diabetes is two to three times more likely to experience a depressive disorder than a person without diabetes (Centers for Disease Control and Prevention, 2021). However, diabetes distress and depression can negatively impact an individual’s self-care abilities and cause symptoms like changes in sleep, appetite, and social relationships, all factors leading to poor diabetes management (Sweatman et al., 2017).

Diabetes-Related distress encompasses four domains: regimen-related, emotional, physical, and interpersonal distress (Wardian & Sun, 2014; Perrin et al., 2017). Statistics have revealed that one in four people with type 1 diabetes has high levels of diabetes distress, and one in five people with type 2 diabetes experiences high levels of diabetes distress (Diabetes UK, 2022).

According to Fisher et al. (2014) and Hendrieckx et al. (2021), diabetes distress tends to occur on a continuum defined by its content and severity. Moreover, this emotional distress, to a greater or lesser degree, is part of living with and managing the disease. An individual’s emotional distress can fluctuate over time and may peak during challenging periods. Such challenging periods may include times after the diagnosis, when significant changes were made in the treatment regimen, at diagnosis of complications, or during a worsening of long-standing complications. Diabetes distress can also occur during times of heightened general stress when the added burden of diabetes self-care behaviors becomes too much (Fisher et al., 2019; Hendrieckx et al., 2021).

Patients with diabetes experience psychosocial and emotional issues in response to these prolonged treatments, including worry about complications, fear of hypoglycemia, fatigue regarding poorly controlled blood glucose, worthlessness, the need for support, and access to healthcare (Nguyen et al., 2020). Diabetes distress is rapidly rising due to the higher global burden of diabetes. Prevention and treatment of diabetes and its complications is a crucial factor



that worsens patients' mental health and makes them develop depressive and anxiety symptoms (Bădescu et al., 2016; Naicker et al., 2017; Hendrieckx et al., 2021).

Furthermore, diabetes-related distress involves emotional symptoms that overlap with several recognized mental health conditions, such as depression (Fisher et al., 2014; Skinner et al., 2020). Anxiety and depression are more prevalent among patients with type 2 diabetes mellitus (T2DM) than in the general population (Tran et al., 2021). One in every four T2DM patients is estimated to suffer from depression (Khaledi et al., 2019). Persons with type 2 diabetes, regardless of their depression symptoms, will benefit from self-management support intervention. Diabetes distress and depression may be similar, but they are of different constructs and, thus, require a different approach to assessment and management. Major depression assumes a psychopathological pattern, which refers to how people feel about their life (constant sense of hopelessness and despair). However, diabetes-related distress is more of an expected reaction to the disease (Hendrieckx et al., 2021).

Studies have shown that severe diabetes distress is associated with adverse medical and psychological outcomes. Severe diabetes distress has been linked with poor self-care behaviours, such as reduced physical activity, less healthy eating, nonadherence to medication, and less frequent self-monitoring of blood glucose (Gonzalez et al., 2016; Hessler et al., 2017). Also, severe diabetes distress is associated with elevated A1C (Gonzalez et al., 2016; Hessler et al., 2017; Stahl-Pehe et al., 2019), more frequent severe hypoglycemia (Hendrieckx et al., 2014) and low quality of life (Hendrieckx et al., 2021).

According to Gómez-Pimienta et al. (2019), people with type 2 diabetes mellitus show high emotional distress living with the disease and have a decreased quality of life. A recent meta-analysis suggests the need to implement psychological interventions for decreasing diabetes-related emotional distress (Schmidt et al., 2018; Gómez-Pimienta et al., 2019) in the multidisciplinary treatment of diabetes.

In addition, diabetes distress can be attributed to the social impact of diabetes, such as the stigma, discrimination, or lack of understanding (Tanenbaum et al., 2016). Stigma may be likened to an attribute of a person that differs negatively from culturally defined norms. Stigmatization occurs when a stigma is perceived, resulting in a punitive reaction. Perceived stigmatization, or felt stigma, is when an individual believes others perceive a personal characteristic as deviant and respond unfairly. An individual may experience diabetes stigma when there are negative feelings such as exclusion, rejection, or blame due to the perceived stigmatization of having diabetes from others.

Socially identifiable factors related to diabetes can include insulin injections, blood glucose monitoring, dietary restrictions, obesity, and hypoglycemic episodes, all of which can contribute to the experience of diabetes stigma. Studies examining the psychosocial consequences of being stigmatized have documented that patients with diabetes experience fear, embarrassment, blame, guilt, anxiety, and low self-esteem (Browne et al., 2013; Liu et al., 2017). Patients have reported "looks of contempt" when injecting insulin in public, workplace discrimination, and limitations in travelling and maintaining friendships, resulting from diabetes stigma (Liu et al., 2017). Feeling stigmatized can result in distress and consequently affect diabetes management directly because patients may be less likely to use or adopt recommended therapies, especially those that may be apparent in public, such as taking insulin injections, using an insulin pump, or self-monitoring blood glucose (Liu et al., 2017).



In many cases, people with diabetes avoid full disclosure about their disease to peers, family members, and sometimes healthcare professionals because they fear judgment or blame (Browne et al., 2013).

Diabetes distress can also be experienced with type 2 DM due to financial implications such as the insurance issues and treatment costs of the condition (Fisher et al., 2014; Fisher et al., 2015). The income level of patients with diabetes may contribute to the difficulties in understanding and managing their disease resulting in distress. The high cost of medications and disease-specific care supplies poses a limitation for the proper management of diabetes. The stress of economic inequality can increase the risk of poor glucose control and diabetes complications through the inability of the patients to purchase healthy food, participate in exercise or recreational activities, manage capillary glucose at home, and access the health care system to receive proper treatment.

Living with diabetes is demanding. People with diabetes often worry about the future and possibly serious complications arising from the disease and treatment. Others have reported experiencing guilt and anxiety when diabetes management goes off track (Hendrieckx et al., 2021). Common stressors of type 2 diabetes are more often related to social consequences, food restriction, and obesity (Sturt et al., 2015).

Healthcare professionals should not underestimate the effect of these diabetes-related feelings, as they have far-reaching consequences on the quality of life of an individual diagnosed with type 2 DM. Managing diabetes is a “24/7” activity that encompasses the continual need to engage in recommended self-care behaviours, make pivotal decisions, and take actions that sometimes result in unintended and unsatisfactory health outcomes. Over time, these problems and frustrations tend to lead to “diabetes burnout” and force the individual to disengage from diabetes care.

### **Nursing Assessment of Diabetes-Related Distress**

Identifying patients at risk of developing diabetic complications, and ensuring this does not occur, is a primary outcome of adequate and appropriate nursing interventions. Therefore, nursing assessment and monitoring are critical components of patient safety. Nurses ought to create a therapeutic milieu that provides them with opportunities to make assessments based on increased interactions over time with patients. The diabetes-related distress risk assessment must be conducted within a relationship based on engagement in identifying risk factors, particularly those modifiable through treatment. The prescribed assessment must not be implemented mechanically; hence, it must be implemented via a relationship based on engagement.

Though studies into diabetes-related distress have significantly increased since 1995, there are still some issues around patient screening, diagnosis, and interventions (Owens-Gary et al., 2019). In 2016, the ADA recommended that individuals with diabetes be psychologically assessed for depressive disorders yearly and before insulin is prescribed due to the potentially deadly effects of the medication (ADA, 2016). However, routine screening for diabetes-related distress is not commonly performed during clinic visits. This disconnect between the recommendations and provider screening could be attributed to the little time assigned to spend with patients, healthcare professionals’ lack of understanding or comfort with mental health screenings, and difficulty discerning somatic symptoms from physical symptoms of illness,



making diabetes distress more challenging to diagnose (Owens-Gary et al., 2019). Diabetes distress can also mimic major depressive disorder; thus, an accurate diagnosis is crucial for the patient (Sweatman et al., 2017).

Furthermore, there are several recommended screening tools in the literature to assist nurses in identifying diabetes-related distress and depression, and these include the 2-item and 17-item Diabetes Distress Scale (DDS-2 and DDS-17), the Problem Areas in Diabetes (PAID) and the 5-item World Health Organization Wellbeing Index (WHO-5). In addition, the 9-item Patient Health Questionnaire (PHQ-9) is generally distributed routinely as part of annual comprehensive physical exams; however, this can only diagnose a prevalent depressive disorder. Therefore, without the administration of a precise screening instrument, diabetes distress may go undiagnosed and untreated (Sweatman et al., 2017). Uniquely, the DDS-17 can assist the healthcare giver in determining the specific types of distress if a person tests positive on the shorter Diabetes Distress Scale (DDS-2) tool. It can help distinguish between major depressive disorder and diabetes distress after a positive World Health Organization Wellbeing Index (WHO-5) result.

**The Problem Areas in Diabetes (PAID):** This is a 20-item tool widely used to assess diabetes distress. Each item on this instrument is measured on a five-point Likert scale, from 0 (signifies not a problem) to 4 (signifies a severe problem). The scores for each item on the instrument are summed up, then multiplied by 1.25 to generate a total score out of 100. A total score of 40 or more indicates severe diabetes distress. Also, an individual item score of 3 or more indicates a 'problem area' or concern and should be further explored during the conversation (Polonsky et al., 1995; Polonsky et al., 2005).

**Diabetes Distress Scale (DDS):** This is another widely used tool for assessing diabetes distress. The instrument contains 17 items. A version of the DDS designed explicitly for people with type 1 diabetes (T1-DDS) has also been validated in the U.S. and Canada. Each item is measured on a six-point scale, from 1 (not a problem) to 6 (a very serious problem). Scores on individual items are averaged within subscales (sources of distress) and a total score. Scores of 2–2.9 indicate moderate distress, and those of 3.0 or greater indicate severe diabetes distress (Polonsky et al., 2005; Fisher et al., 2012; Fisher et al., 2015).

## CONCLUSION

Identifying the source of diabetes-related distress is very important in resolving it because the extent to which diabetes distress is stabilized or changes over time varies depending on the source of the distress. If untreated, mild diabetes distress often persists and may develop into severe diabetes distress or depression.





## RECOMMENDATIONS

1. Nurses should integrate psychosocial care with collaborative, patient-centered care for all people with diabetes to optimize health outcomes and health-related quality of life.
2. Nurses should consider an assessment of symptoms of diabetes distress, depression, and anxiety using patient-appropriate standardized/validated tools at the initial visit, at periodic intervals, and when there is a change in disease, treatment, or life circumstance. Including caregivers and family members in this assessment is of great importance.
3. Nurses should monitor patients' performance of self-management behaviors as well as psychosocial factors impacting self-management.
4. Nurses should assess a patient's life circumstances that can affect physical and psychological health outcomes and incorporate them into intervention strategies.
5. Nurses should immediately address psychosocial problems upon identification. Suppose an intervention cannot be initiated when the problem is identified during the visit. In that case, a follow-up visit or referral to a qualified behavioral health care provider may be scheduled.
6. Nurses must ensure that diabetes-related distress risk assessment must be conducted within a relationship based on engagement.
7. Enhancing the understanding of the lived experience of older adults with diabetes-related distress may allow nurses and policymakers to tailor treatment to this population, thus improving the health-related quality of life (HRQoL) of patients diagnosed with type 2 diabetes mellitus.

## DECLARATIONS

### Competing Interests

The author declare there is no conflict of interest, This work did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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