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EDIT (Early Detection and InTervention) Diabetes Distress South Asian federation of endocrine societies (SAFES) Recommendation and Responsibilities

Abstract

Living with diabetes can be challenging and often involves a significant burden on individuals' daily lives. Diabetes management requires constant attention and efforts to maintain blood glucose levels within a healthy range. In addition to the physical demands of diabetes management, individuals with diabetes may also experience emotional and psychological burdens, commonly referred to as diabetes distress. Diabetes distress and the burden of living with diabetes can have a significant impact on an individual's overall health and well-being. It is important for individuals with diabetes to seek support and assistance from healthcare professionals, family, friends, and support groups to manage their diabetes distress and maintain their overall emotional and physical health. Early detection and intervention for diabetes distress are crucial for improving diabetes self-management and emotional well-being, preventing burnout, reducing healthcare costs, and improving the overall quality of life for individuals with diabetes. In the south Asian region, there is limited research specifically focussed on diabetes distress. So, the South Asian Federation of Endocrine Societies (SAFES), which is an association of Seven national professional bodies in South Asia, aim to bring together recommendations and responsibilities towards early detection and intervention for diabetes distress.

Keywords: Humans, Friends, Quality of Life, South Asian People, Burnout, Psychological, Attention.

1.Introduction

Alarmingly, Diabetes is present as a global epidemic. As per International Diabetes Federation, 537 million adults (20-79 years) worldwide were affected by diabetes in 2021, and it is expected to reach 643 million by 2030 and 783 million by 2045.[1] India alone has 74 million people with diabetes in the age group of 20–79 years. A meta-analysis reported 12.13% prevalence of diabetes in Afghanistan[2], which is higher than in Bangladesh[3] (7.8%) and Nepal (8.4%)[4], while lower than in Pakistan (14.7%)[5]. Among SAFES countries, in 2021, the Word Bank-International Diabetes Federation reported highest prevalence of diabetes in Pakistan (30.8%), followed by Bangladesh (14.2%),SriLanka(11.3%), Afghanistan(10.9%), India (9.4%), Maldives (9.2%) and Nepal(8.7%).[6]

Most of the guidelines on diabetes care focus on the pharmacological aspect of initial management without addressing the patient's psychological needs.[7] However, many people with diabetes live a healthy life but struggle to optimise their diabetes control, often because of psychological and social problems or comorbid mental illness. Disorders such as anxiety[8], depression[9], diabetes distress[10,11] and poor eating habits[12] have been found to occur with greater frequency in people with diabetes. The second Diabetes Attitudes, Wishes and Needs (DAWN2) study, which aimed to assess psychosocial outcomes in people with diabetes across countries, reported that diabetes harms emotional well-being (46.2%).[13]

Living with diabetes is a lifelong stress and requires dealing with psychological issues. The psychological reactions of patients towards diabetes can be categorised under four basic levels of emotional distress[14,15] which include emotional reactions (shock, denial, anger, guilt, and anxiety), diabetes distress, phobia reactions including fear of insulin, the need for injection, hypoglycaemia, later complications, and obsessive behaviour) and psychiatric disorders. Beeney et al. found that patients were distressed at the diagnosis, with emotions ranging from anxiety, shock, anger, or denial.[16]

The DAWN study emphasised that psychological support in diabetes patients is under-resourced and inadequate, resulting in poor quality of life (QoL) and reduced general well-being. Psychosocial problems eventually lead to depression or other mental disorders associated with poor self-care behaviour, poor metabolic outcomes, increased mortality, functional limitations, increased healthcare costs, loss of productivity, and reduced QoL.[15]

Diabetes has been identified as a risk factor for poor mental health in the geriatric population. A study done by the All India Institute of Medical Science (AIIMS), New Delhi, India, has proved that diabetes is a risk factor for poor mental health illness in the elderly population. The prolonged medication in the aging population showed a

significantly higher frequency of depression (35.6% vs 16.7%), Generalized anxiety disorder (GAD) (12.8% vs 4.4%), and cognitive impairment (53.9% vs 27.2%) compared to non-diabetics[17]. Social isolation of older adults is an additional risk factor for poor mental health. A meta-analysis of studies focused on people with diabetes aged 60 years and above found that 28% to 49% of this population engaged with others less than once per week.[18]

As mentioned in Table 1, the evidence base for the interrelationship of diabetes with mental illness has increased over the past 22 years.

Table-1: The evidence base for inter-relationship of diabetes with mental illness[9,19-22]

Ref.	Outcome (depression/anxiety)
2001, Anderson et al.[9]	A meta-analysis indicated that presence of diabetes doubled the risk of comorbid depression
2009 Schram MT et al.[19]	Diabetic individuals with depressive symptoms also had a severely lower diabetes-specific quality of life.
2012, Roy and Lloyd et al.[20]	Rates of depression in people with type 1 and type 2 diabetes are three times and two times than those in the general population, respectively.
Park et al., 2013 [21]	A hazard ratio of 1.5 (1.35–1.66) for all-cause mortality in depressed patients with diabetes
Smith et al. 2013 [22]	Odds ratio (OR) for anxiety disorder was 1.20 (1.10–1.31) and for anxiety symptoms 1.48 (1.02–1.93), whereas the pooled OR was 1.25 (1.10 –1.39)

1.1 Mental Health and Its Impact on Diabetes Management

In Type 2 diabetes mellitus (T2DM), psychological stress deploys biological responses, which include the release of glucose and lipids into the circulation, inflammatory cytokine expression and increased blood pressure. Repeated or sustained stress dysregulates glucose metabolism, neuroendocrine function and chronic low-grade inflammation and predicts incidents of T2DM. Depression in the context of diabetes is also associated with poor self-care for diabetes treatment (non-adherence), poor glycaemic control and more long-term complications.[23] Serious anxiety disorders largely overlap with the symptoms of hypoglycaemia, making it difficult for the person with diabetes to differentiate between feelings of anxiety and symptoms of low blood glucose that require immediate treatment.[24] Fear of hypoglycaemia, a common source of severe anxiety for persons with diabetes, can lead some patients to maintain blood glucose levels at above-target levels.

Diabetes is commonly 'overshadowed' by mental illness. People living with co-morbidity, and staff supporting them, cannot always distinguish between symptoms of severe mental illness and diabetes. A qualitative study as a part of the EMERALD project mentioned that managing diabetes becomes difficult when severe mental illness or physical health deteriorates, and more intensive support for diabetes management is needed when people's severe mental or physical health deteriorates.[25]

Diabetes distress, a syndrome-specific condition unique to diabetes, is properly termed a diabetes adjustment disorder, defined as a perceived inability to cope with the demands and challenges of living with diabetes.[26]

All these mental dysfunctions have a bidirectional relationship with hyperglycaemia. While diabetes is linked with a higher burden of psychological and psychiatric dysfunction, depression and anxiety are worsened by hyperglycaemia.[22]

1.2 Euthymia- Tool as well as a target for diabetes care.

The Greek philosopher Democritus defined the word euthymia ('eu' = well + 'thymos'= soul/emotion) as ''*One is satisfied with what is present and available, taking little heed of people who are envied and admired and observing the lives of those who suffer and yet endure*.''[27]

Euthymia is an optimal mental state or mood that conveys a sense of healthy life and coping with diabetes. This can be measured objectively by validated tools, including the World Health Organization- Five Well-Being Index (WHO-5). Euthymia should be considered an important tool and target in diabetes care as the burden of mental health dysfunction is high in DM patients. Euthymia emphasises the importance of maintaining sufficient balance among important life domains and displaying compatibility in one's behaviour throughout the DM management. Kalra S et al. have developed a model focusing on self-care skills in diabetic patients and patient–provider communication to enhance coping skills. (Fig-1).[28]

1.3 Impact of Distress on Family

Diabetes results in burden, worry and distress for adult family members of people with diabetes. The second

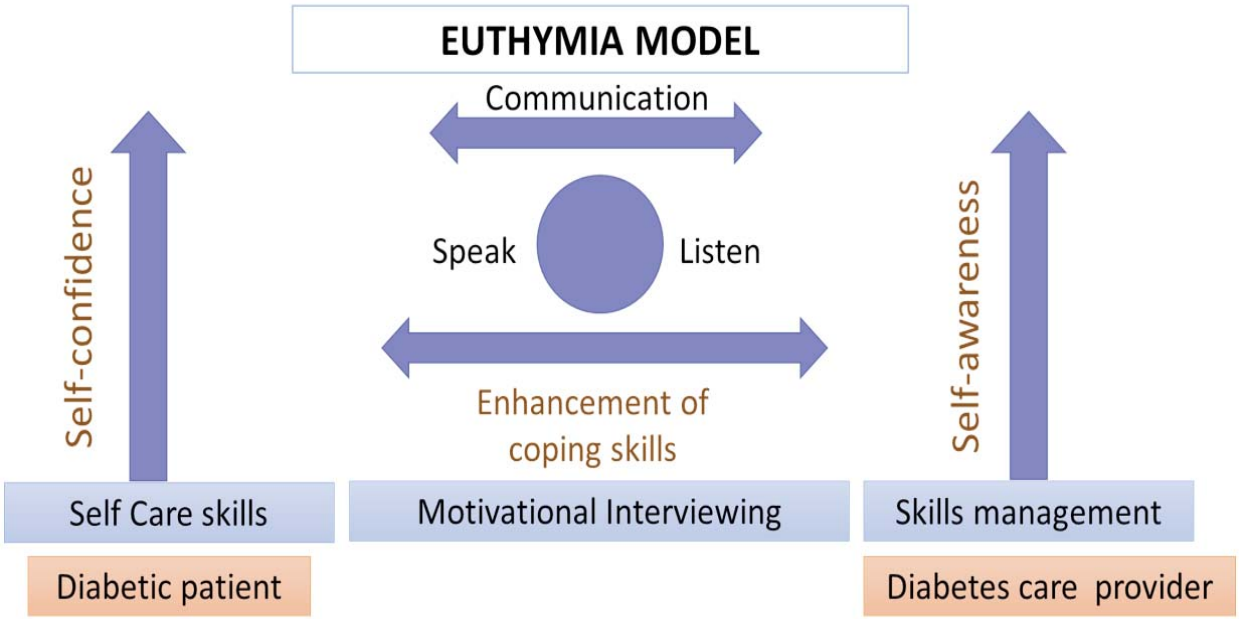


Figure-1: Euthymia model[28]

DAWN2 study surveyed adult family members of adults with diabetes across 17 countries to examine their experiences[29]. They found that diabetes has a negative impact on a wide range of life domains of family members.[30,31] Forty five percent felt a high level of distress related to thinking about the person with diabetes, 35.3% reported a 'moderate' to 'very large' burden in helping the person they live with manage their diabetes, and 61.3% were worried about the risk of hypoglycaemic events.[31]

1.4 Financial cost of diabetes and Its effect on mental Health

The high cost of diabetes care generated barriers that negatively affected physical and emotional health.[31] Patients with diabetes and comorbid mental disorders show increased hospitalisation rates and hospitalisation costs, frequency and costs of outpatient visits, emergency department visits, medication costs and total healthcare costs compared with diabetic patients without such problems.[32-34].

2.0 Diabetes Distress (DD)

DD is a psychological state that is a unique, often hidden, emotional burden and worry that a patient experiences when managing a severe chronic disease such as diabetes. This is found in persons with diabetes and their caregivers. DD has been defined across domains relating to (1) diabetic regimen, i.e., the monitoring of blood glucose, dietary control, and increasing physical activity; interpersonal or relational issues, referring to conflicts with carers, partners, and friends; and (2) emotional burden, i.e., feeling demotivated, unsupported emotionally, misunderstood and worrying about future complications. Table 2 shows the definition of DD by

Table-2: Definitions of DD.

Author	Definition
Kreider (2017) [35]	An emotional state where people experience feelings such as guilt, stress, or denial that arise from living with diabetes and the burden of self-management
Gonzalez et al. (2011)[36]	Unique, often hidden negative emotional reactions experienced by the patient when managing diabetes.
Fisher et al. (2012) [37]	Significant emotional reactions to the diagnosis, threat of complications, self-management demands, or unsupportive social structures surrounding diabetes.
	Fears of complications, worries about hypoglycaemia, and the variety of stresses, strains, and concerns people with diabetes have on a day to day basis.
	Existence of DD in family members who care for persons with diabetes.
Kalra 2018 [38]	Emotional response characterised by extreme apprehension, discomfort, or dejection, due to perceived inability to cope with the challenges and demands of living with diabetes.

different authors.[35-38]
DD is a state which causes significant emotional distress; however, it fails to meet the diagnostic criteria for major depressive disorder (MDD). Diabetes distress and depression can exist separately or co-occur (Table 3).

Table-3: Differentiation between diabetes distress and depression[39]

Parameter	Diabetes Distress	Depression
Definition	Mainly an effective response to diabetes morbidity and burden of the disease	A complex response and involves a range of other reactions dissimilar from the affective response
Response	Include worry, guilt, fear, sadness, anger, frustration and, burnout	Include cognitive, affective, social, motivational, vegetative, and interpersonal disturbances
Prevalence	Greater	Relatively lesser
Relation between diabetes and diabetes distress	seem to be linearly related	seem to have reciprocal connection in many cases
Is a significant risk factor for developing medical complications?	Not	Yes
Associated with HbA1c levels	Relatively consistently association	No association
Interventions	Psychoeducation, supportive therapy, counselling, and other simple behaviour management methods	Complex psychological interventions such as CBT and ACT

Diabetic patients with comorbid depression are more likely to develop clinical complications than non-depressed patients.[40]

2.1 Epidemiology of Diabetes Distress

Worldwide DD may affect as many as 40% of people diagnosed with diabetes[14] As per community-based studies, DD may occur in up to 45% persons with type 2 diabetes mellitus[15]. A cross-sectional descriptive study in a noncommunicable disease clinic of a tertiary care medical centre in India reported 42% DD in nondepressed type 2 diabetes mellitus[41]. Based on evidence from meta-analysis, systematic reviews, narrative reviews, and empirical studies for distress and depression reported, ~20–40% of people have elevated or severe diabetes distress.[42] A cross-sectional study in Bangladesh showed a high prevalence of DD in patients with T2DM; 52.5% had DD, 29.7% had moderate, and 22.8% had high DD.[43]
The prevalence of diabetes distress varies greatly across different populations of people with diabetes.[44-48] (Table-4).

Table 4: Prevalence data of Diabetes Distress.

Study	Type	Conclusion/Result
Perrin NE 2017 [44]	Meta-analysis	Overall prevalence of 36% diabetes distress in people with T2DM.significant associations between higher distress and female gender
Joensen LE 2013 [45]	Cross-sectional survey	Association of psychosocial distress among adults with T1DM
Fisher L 2015 [46]	Qualitative interviews	Younger people and people with shorter diabetes duration more often experience diabetes distress than older people and people with longer diabetes duration, both in people with T1DM and those with T2DM
Peyrot M 2014 [47]	Retrospective study	Association between higher istress and ethnicity, with non-white people and ethnic minority groups having a higher prevalence of diabetes distress than white people and non-minority groups
Lohiya et al. 2020 [48]	Cross-sectional study	Prevalence is higher in Indian mothers than children

2.2 Etiology of DD

The main factors contributing to DD are self-perception of inadequacy and uncertainty, poor opinion of the accessibility and/or ability of the diabetes care professional, and dissatisfaction with social support. Figure 2 shows different factors related to patients, family and friends and caregivers or physicians contributing to DD.[15]

Qualitative interviews with 25 T1DM adults and 10 diabetes health care providers and factor analytic procedures derived seven major sources of diabetes distress: Powerlessness, Negative Social Perceptions, Physician Distress, Friend/Family Distress, Hypoglycaemia Distress, Management Distress, and Eating Distress. (Table 5).[46]

During changes in life, disease state, health care, and disease management, the risk of DD is very high. Figure 3 shows precipitating factors of diabetes distress.[43]

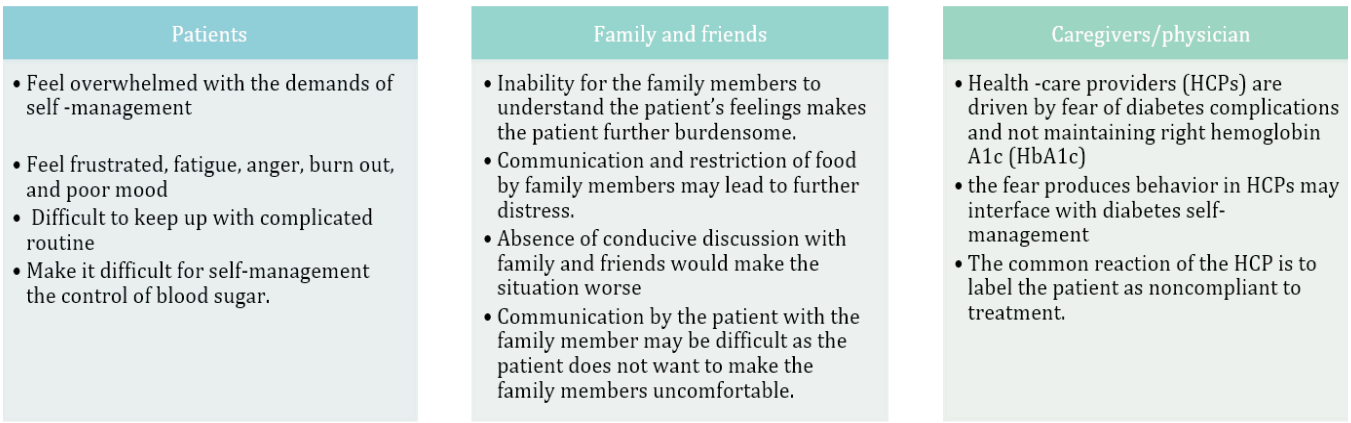


Figure-2: Factors contributing to DD.

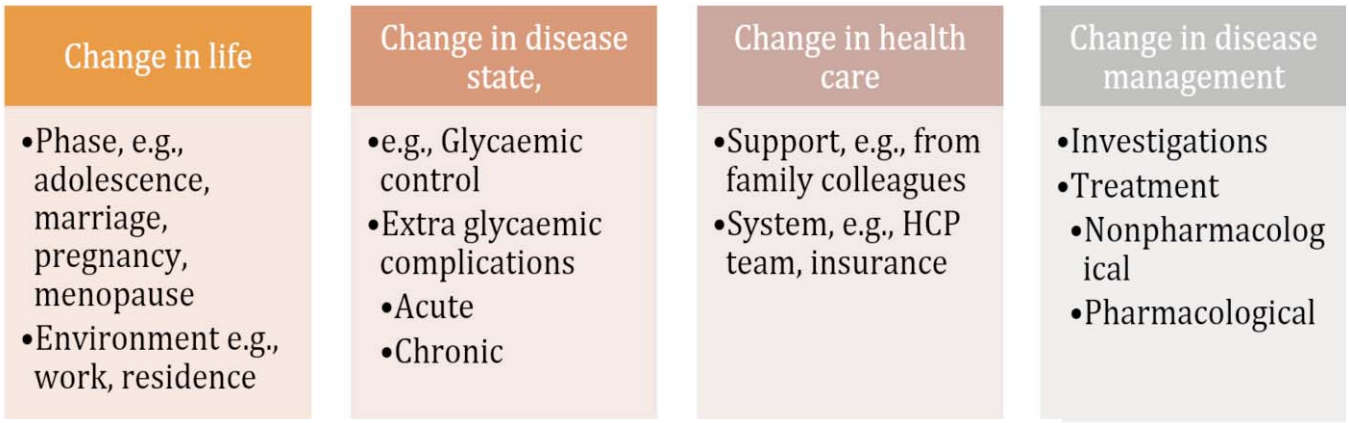


Figure-3: Precipitating factors of diabetes distress.

A cross-sectional study at the Pakistan Institute of Medical Sciences, Islamabad, identified the associated factors for DD prevalence among T2DM patients. Total diabetes distress was significantly related to the demographic background, education level, monthly income, frequency of administration of medication, adherence to medical treatment, number of complications and overall glycaemic control ($p<0.05$ for all).[49]

Table-5: Major sources of diabetes distress among adults with T1DM[46]

Author	Definition
Powerlessness	A broad sense of feeling discouraged about diabetes
Negative Social Perceptions	Concerns about the possible negative judgments of others
Physician Distress	Disappointment with current health care professionals (mistrust and incompetence)
Friend/Family Distress	There is too much focus on diabetes amongst loved ones
Hypoglycaemia Distress	Concerns about severe hypoglycaemic events
Management Distress	Disappointment with one's own self-care efforts
Eating Distress	Concerns that one's eating is out of control

2.3 Symptoms of DD

The symptoms of DD are like those of depression but are not severe enough to qualify as major depressive disorder (MDD). Some of the core symptoms of DD are listed in figure 4.

2.4 Detection of DD

2.4.1 Screening and diagnostic tools

DD can be detected using validated screening and diagnostic tools[50], as mentioned in Table 6.

Dudley A. et al. researched and analysed results from demographic survey questions and the DDS-17 and identified the areas of statistically significant distress in people recently diagnosed with diabetes[51]. DDS provides a quantitative assessment of the degree of DD but its utility as a constructive platform to build upon

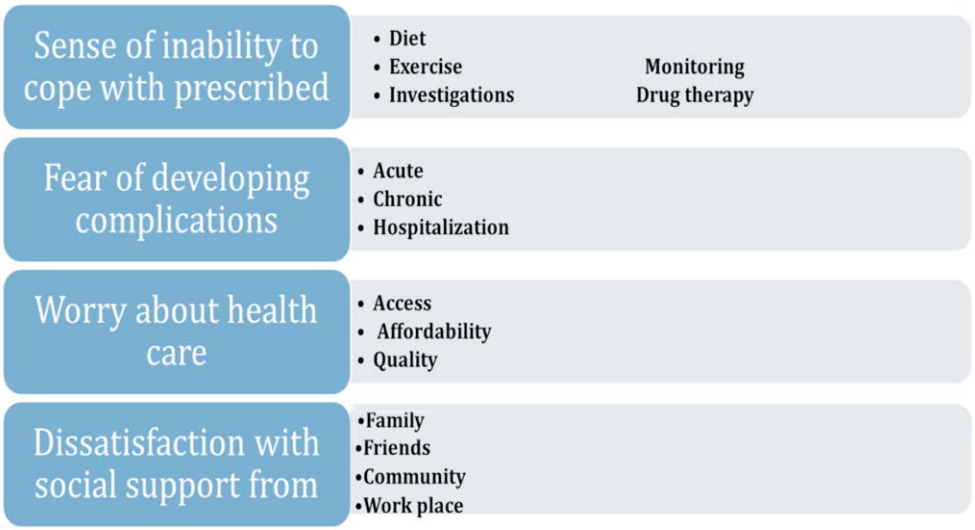


Figure-4: Core symptoms of diabetes distress [37]

Table-6: Screening and diagnostic tools for DD

Measure	No. of domains	No of items	Time to complete	Scoring
Diabetes Distress Scale (DDS)	4	17	10-15 min	2.0-2.9 = moderate distress; ≥ 3 = high distress (items rated as "serious" or "very serious" warrant clinical attention)
DDS-2	1	2	1min	Average ≥ 3 or total ≥ 6 = moderate to high distress
Type-1 DDS	7	28	10-15 min	1.5-1.9 = low distress; 2.0-2.9 = moderate distress; ≥ 3 = high distress (items rated "serious" or "very serious" warrant clinical attention)
Problem Areas in Diabetes (PAID)	1	20	10-15 min	Score 0-100; ≥ 40 indicates high distress (items rated "serious" warrant clinical attention even if score < 40)
PAID-5	1	5	5 min	Score 0-20; ≥ 8 indicates high distress (items rated "serious" warrant clinical attention even if score < 8)
PAID-1	1	1	1 min	≥ 3 indicates high distress

Scores	Coping Mechanism	Explanation	
Positive score	Acceptance	How well do you accept diabetes as a part of your life	Answers on a scale of 1-10 (1 being never and 10 being always)
	Optimism	How often do you have pleasant or positive thoughts	
	Planning	How well do you plan strategies to manage diabetes	
	Action	How often do you take positive actions to manage diabetes or to manage life	
Negative score	Negativity	How often do you get stuck in extremely negative or persistently negative thoughts?	
	Blame	How often do you blame yourself or others for diabetes	

Figure-5: The GlucoCoper – a Tool for the Assessment of Coping Mechanisms. [53]

therapeutic interventions or plan further management is restricted by its structure. It is not designed to identify specific shortcomings or weaknesses in coping styles that can be targeted to improve the emotional health of patients with DD. In this situation, the ability to cope with diabetes is a tool, as well as a target, of effective diabetes care, coping, or control skills in diabetes can be studied as a positive corollary of glycaemic control, rather than focusing on the negative.

The GlucoCoper is a tool for the assessment of coping mechanisms.[52] This tool contains six common coping mechanisms (two negative and four positive). The GlucoCoper is simple to understand, easy to administer, and visually appealing. (Figure-5) The scores of the four positive coping mechanisms (acceptance, optimism, planning and action) are added to calculate the positive scale score, and the scores of the two negative coping methods (resistance and blame) are added to form the negative scale score. The negative scale score is subtracted from the positive scale score to calculate the total coping score.

GlucoCoper was identified as an effective screening tool for dysfunctional coping skills in pregnancy complicated by diabetes.[53]

2.5 Initiating the discussion

Even after establishing proper measures for diabetes distress, conversation about their coping with and feeling about various aspects of their diabetes to identify emotional distress is important. Though discussion of psychological issues is outside medical healthcare, time restrictions are also a major obstacle in facilitating such conversations. Beverly E. A. et al. reported that individuals with diabetes who were less likely to discuss self-care issues (30% of the entire sample) reported higher diabetes distress, poorer quality of life, less frequent self-management behaviours and less self-motivated coping strategies[54]. An informal way of conversation does not require psychological expertise and does not require providing solutions there and then. Just initiating normal conversation, listening to, and showing an understanding and awareness of the psychosocial and emotional issues that often go unnoticed and grow.

2.6 Diabetes fatigue

Fatigue refers to the physical and mental or sexual weakness caused by stress, illness or disease, work overload, or various medications. Patients may have difficulty performing daily activities, leading to reduced quality of life. Fatigue has a varied clinical presentation and is commonly associated with chronic diseases such as diabetes.[55, 56] A cross-sectional study in a tertiary care referral hospital in India reported a 68% incidence of fatigue in type 2 diabetes patients, which was almost 10 times higher than the healthy controls.[57] Though fatigue is commonly encountered in diabetes care, it is often neglected. Fatigue can be a presenting symptom of diabetes; on the other hand, easy fatigability can cause diabetes distress. This bidirectional relation between diabetes and fatigue (Figure 6) leads to the vicious cycle of diabetes fatigue syndrome (DFS). DFS is a multifactorial syndrome caused by lifestyle, nutritional, physical, mental, glycaemic, endocrine, and iatrogenic factors[56] Diabetes fatigue can be present in both T1DM and T2DM patients.[55]

The causal link between diabetes and fatigue is largely mediated by biochemical factors and lifestyle and

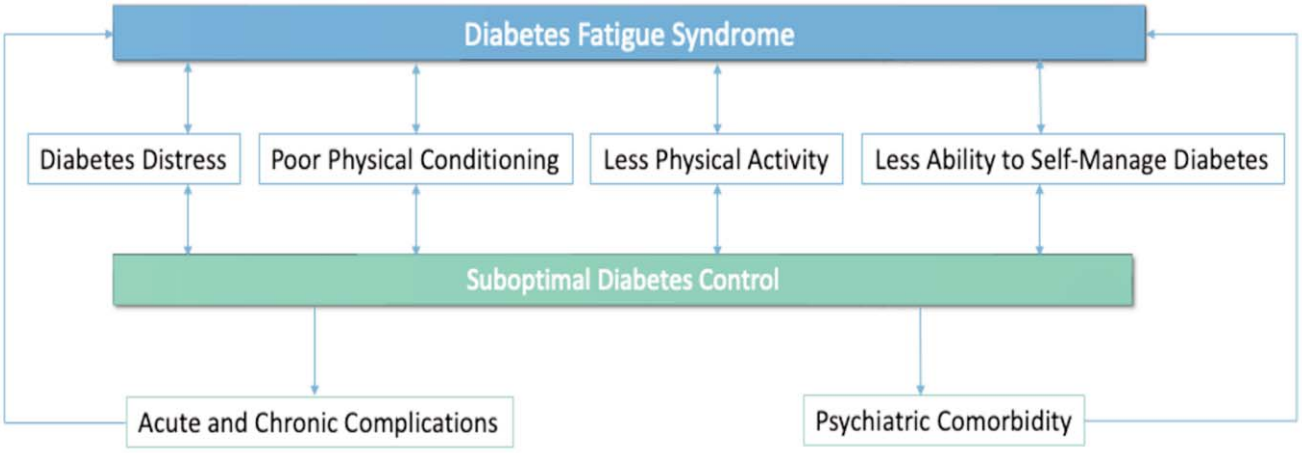


Figure-6: The bidirectional relationship between fatigue and diabetes creates the vicious cycle of DFS. (Adapted from Kalra et al. 2018[55]

psychological factors. Certain ionic changes, such as high concentrations of inorganic phosphates and hydrogen ions, imbalance of potassium ions, and substrate depletion, impact muscle contractility. The decreased availability of calcium ions for release from the sarcoplasmic reticulum leads to low ATP synthesis, thus causing fatigue.[58] Relative insulin deficiency in diabetic patients tends to alter the energy substrate from carbohydrates to fat utilisation. Once the glycogen stores are depleted, the ADP phosphorylation is impaired. Consequent inhibition of ATP resynthesis due to the non-availability of ADP predisposes to fatigue.[55]

2.6.1 Causes of fatigue in people with diabetes

The etiological factors of fatigue can be broadly divided into non-endocrine and endocrine factors. Non-endocrine factors such as an unhealthy and sedentary lifestyle, poor sleep hygiene, and drug abuse should be identified through careful history taking. A comprehensive diet history helps identify diet-related factors. Certain medical conditions such as multivitamin deficiencies, anaemia, and dyselectrolytemia are some comorbid causative factors of DFS. Diabetes is a chronic disease that has a strong correlation with psychological impairment.[55] "Diabetes emotional distress" is burnout that people with diabetes experience due to the overwhelming and frustrating burden of diabetes self-care.[59] The perceived inability to optimally self-manage diabetes can cause diabetes distress which may be reported as fatigue. Once the non-endocrine factors have been eliminated, a targeted gluco-endocrine evaluation must be done to identify the aetiology of DFS. Diabetes-related factors such as suboptimal glucose phenotype encompassing the hexad of postprandial hyperglycaemia, recurrent hypoglycaemia, and excessive glycaemic variability, along with high levels of glycated haemoglobin can cause DFS and may even persist after glycaemic control. Similarly, diabetic complications like nephropathy, neuropathy, myopathy and cardiopathy can be adversely associated with fatigue. Concomitant endocrinopathy, including hypothyroidism, hypogonadism, Cushing's syndrome and Addison's disease, if unidentified or inadequately managed, can worsen DFS, especially in type 1 diabetics.[55] Statins have been reported to induce significant unfavourable effects on energy and exercise performance. Decreased oxidative capacity of muscle mitochondria induced by statin use can lead to fatigue during exertion. Statin-associated muscle symptoms were observed with modest doses.[60, 61] Chronic corticosteroid use induces diabetogenic effects in skeletal muscles causing DFS.[62] The role of beta blockers as an iatrogenic cause of DFS must also be evaluated.[55]

2.6.2 Relationship between glucose levels and fatigue

The increased propensity of fatigue in diabetic patients has been primarily related to abnormal glucose levels due to impaired glucose metabolism.[63] Gender differences in glucose excursion-related fatigue have also been reported with women exhibiting higher baseline fatigue scores than men ($p<0.01$). Women presented with higher fatigue levels for three of the five study days and throughout the day except for mornings than men ($p<0.05$). Average weekly fatigue levels significantly correlated with average weekly glucose levels in women ($p=0.016$) but not men.[64] Hyperglycaemic symptoms were reported by 90.2% diabetic people treated with insulin. These were based on principle component analysis. Tiredness was ranked third among the sixteen most reported symptoms. Tiredness correlated with lower levels of hyperglycaemia and frequently preceded osmotic symptoms like thirst or excessive urination.[65] An epidemiological population-based study conducted on 1137 newly diagnosed diabetics revealed a 61% prevalence of fatigue. Fatigue was experienced by 5.6% subjects for more than a year, while 2.6% subjects had fatigue for over two years at the time of diagnosis. Fatigue was significantly associated with fasting plasma levels but not glycated haemoglobin levels.[66] High levels of fatigue have been associated with acute hypoglycaemic episodes. Higher fatigue symptoms and decreased well-being were observed the morning following the hypoglycaemia episode. Subjects were also more likely to experience fatigue more rapidly during an exercise bout corresponding to higher blood glucose levels.[67] A cross-sectional descriptive study assessed correlations between HbA1c levels and fatigue. In the group with HbA1c >7%, fatigue was indirectly related to HbA1c. In the group with HbA1c ≤ 7% fatigue was not related to HbA1c directly or indirectly, rather it was related to diabetes distress and diabetes symptoms. In both groups, the severity of diabetes was the strongest predictor of fatigue.[68]

2.6.3 Diabetes fatigue and the importance of sleep

It has been established that fatigue significantly affects sleep apnoea in individuals with diabetes. Individuals with diabetes reported higher fatigue scores in a questionnaire-based assessment compared to the non-diabetic group. The Pittsburgh Sleep Quality Index score was significantly higher in the diabetes group than in the healthy controls ($p=0.043$)[63]. A cross-sectional questionnaire-based study observed significantly higher

stress levels in diabetic patients than in non-diabetic individuals (p=0.010). The prevalence of sleep issues and a feeling of fatigue or lack of energy was significantly higher in the diabetic group (both p<0.001). Treated diabetics also displayed a similar trend with significantly more sleep problems (p=0.0003) and fatigue (p=0.0004).[69] Sleep quality has been reported as the strongest predictor of fatigue in people with diabetes.[70]

2.6.4 Approach to diagnosing diabetes fatigue syndrome

DFS is a multifaceted condition involving an interplay of numerous factors. Thus, a systematic strategic diagnostic plan must be followed (as shown in Figure 7) rather than a pure gluco-centric or endocrine-focused approach.[55]

Along with glycaemic status, the biochemical and psychological aspects should be addressed. Lifestyle history and diet-related factors should be assessed before investigating endocrine dysfunctions or any medical condition. Nutritional deficiencies, sleep quality, level of physical activity, and disturbances in electrolyte balance are to be noted. Screening is performed to identify diabetic complications. A detailed medication history helps to rule out any iatrogenic causes. Hypoglycaemia-induced fatigue improves by food consumption, while fatigue during the early hours of the day indicates nocturnal hypoglycaemia. Diabetes distress must be ruled out before investigating for psychiatric conditions.[55]

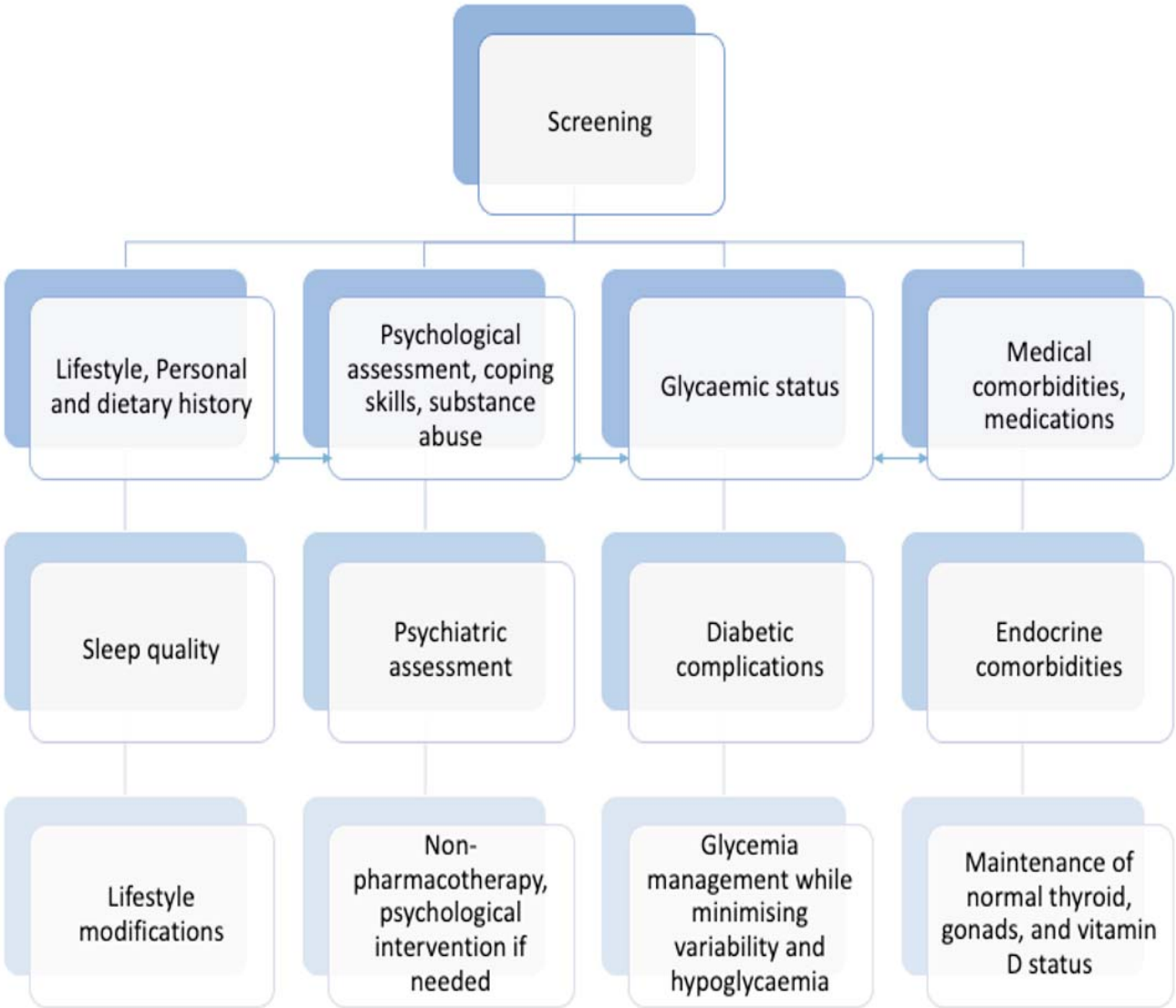


Figure-7: Clinical strategy to address DFS (adapted from Kalra et al. 2018 [55]

2.7 Diabetes distress in Special conditions/Population

2.7.1 Children and adolescents

Diabetes distress is one of the most important psychological factors responsible for the overwhelming burden of childhood diabetes. Diabetes in children translates to life-long food restriction and insulin-dependence, which is cumbersome and distressing.[71]

Regular scheduled diabetes appointments, monitoring risk and medical complications, controlled physical activities, and actively maintaining a healthy immune system to ward off infections are some of the demanding tasks children with diabetes must go through in contrast to their non-diabetic counterparts. Children may miss social functions or need to participate in a limited fashion due to their condition, which makes them feel singled out.[71]

Adolescence is a challenging time, particularly so for adolescents with diabetes who must deal with the impending distress of daily diabetes monitoring in addition to the physical, psychological, and social changes to become an independent youth.[72] The hormonal changes during puberty make it even more difficult to manage diabetes and can also accelerate the onset of complications.[73]

Not only children but also their families, especially parents or caregivers, are affected by the ongoing stress and chronic sorrow. For young children, their parents manage the child's diabetes and supervise all diabetes-related tasks. Perceived inability to optimally perform diabetes-regimen-specific duties and decisions causes parents' psychological distress, which can negatively affect the child's illness management.[74]

Therapeutic activities such as regular use of continuous glucose monitoring systems, a constant vigilance of the carbohydrate levels in the child's food, daily adjustment of insulin doses and injecting insulin, and operating insulin pumps, coupled with social distress, increase the risk of diabetes-associated stress.[75]

Female's gender, low socio-economic status, and less-educated parents are more susceptible to diabetes-associated psychological stress.[76] A questionnaire-based Indian study on children and adolescents between eight to eighteen years of age observed a significantly higher mean diabetes distress score in mothers than in their offspring.[48]

Another study evaluated the psychometric properties of the child- and parent-reported measures of the Problem Areas in Diabetes Scale. At least one item on the scale as a diabetes-specific emotional problem was reported by 40% of children aged 8-12 years, 26.8% felt that their friends and family do not understand the difficulty of living with diabetes, whereas 61.1% parents reported serious diabetes-related emotional concerns, and 36.6% were anxious about the future and incidence of serious complications.[77]

A cross-sectional study on 117 Pakistani[78] adolescents with type 1 diabetes reported higher scores of powerlessness, eating distress and negative social perception, with females presenting with higher distress levels than males. Diabetes-related distress was higher in those with teen-onset diabetes than childhood onset diabetes.

The Teenagers on Diabetes Sweden (TODS) study (73) observed that gender was highly correlated with distress level even when controlling for multiple factors that may affect distress ($P = 0.0003$). Young women scored significantly higher ($p<0.0001$) on the diabetes regimen distress subscale.

The secondary analysis of the diabetes prevention trial in 264 adolescents (mean age of 15.7 years) with type 1 diabetes observed chronic, elevated diabetes-related emotional distress (DRD) in almost 1/3rd of the youth.[79]

Hoffman RP et al. assessed depression and distress scores in 364 adolescents between 13 and 17 years of age. The scores for diabetes distress were higher in male adolescents with type 2 diabetes than those with type 1 diabetes, but no such differences were observed in adolescent females. Diabetes distress scores significantly correlated with type 2 diabetes ($p<0.0001$). Unlike type 1 diabetes, distress screening scores were not related to glycaemic control in type 1 diabetes.[80]

2.7.2 Screening tool for DD in children/Adolescent

The Problem Areas in Diabetes – Parent version (PAID-P) measure perceived parental burden associated with caring for a child with diabetes. The PAD-P has demonstrated associations with diabetes-specific family conflict and quality of life[81]. The teen PAID (PAID-T) is a companion to the PAID-PR for use in younger patients as well as teens, spanning the age group of 8–17 years.[82]

2.7.3 Young adult

Diabetes-specific distress is common in the second phase of young adulthood ranging between 23 to 30 years. One of the most common factors that induce distress in this population is the feeling of self-consciousness about diabetes which is generally strong during the first phase (18-22 years) of young adulthood. Young adults have strong stigma-related perceptions, which make them avoid activities that would highlight or reveal their diabetes. It is perceived that the media portrays a prototypically negative view of diabetes linking it to moral failings in lifestyle management.

Type 2 diabetes is being paid more attention by agencies and policy reformers who constantly neglect type 1 diabetes. Most young adults find day-to-day diabetes management difficult. Difficulty in diabetes control, hypo- or hyper-glycaemic states, and poor diabetes control have a negative psychological impact.

Most young adults experience a limiting influence of diabetes, due to which they struggle to balance their diabetes and daily activities. The paucity of integrated healthcare services, insufficient continuity of care, having to fight the healthcare system, apprehensions about managing pregnancy with diabetes and concerns about the future are other factors associated with diabetes distress in young adults. Participants in a qualitative study by Balfe et al (2013) felt that that having an opportunity to consult healthcare professionals in relation to their diabetes distress must be a part of diabetes management.[83]

2.7.4 Elderly population

Older adults with type 2 diabetes are at elevated risks of comorbidities and diabetes-related distress more than younger adults because this population presents the unique emotional burden of living with diabetes associated with worry, frustration, and burnout. Diabetes-associated symptoms such as hypoglycaemia, fatigue and neuropathic pain are strong predictors of diabetes-specific stress.

An interpretive phenomenology-based study sampled the elderly with type 2 diabetes and over 65 years of age. Common DD-related symptoms observed in the participants were fatigue, diarrhoea, hypoglycaemia, pain, lack of balance, and falling. These DD-associated symptoms caused a decreased quality of life, a substantial lack of independence, and restricted activities.[84]

A cross-sectional, descriptive, home-based study in 338 low-income individuals over 60 years of age evaluated emotional distress in type 2 diabetes based on Problem Areas in the Diabetes questionnaire. Most participants (35.2%) revealed that concerns regarding their future and the likelihood of developing serious complications were their main problems. The high level of emotional distress was found to be associated with self-perception of health, age at diagnosis, the number of diseases associated with diabetes, use of insulin only or along with oral anti-diabetic drugs, self-efficacy, and renal dysfunctions.[85]

Self-efficacy ($p<0.01$) has been reported as the strongest predictor of diabetes distress in older individuals 60 years old and above. Based on stepwise regression analysis, spirituality, non-supportive family environment, and blood sugar levels are significant (all $p<0.05$) contributing factors to diabetes distress.[86]

2.7.5 Diabetes distress and marriage

Khandelwal D et al in their review found individuals with

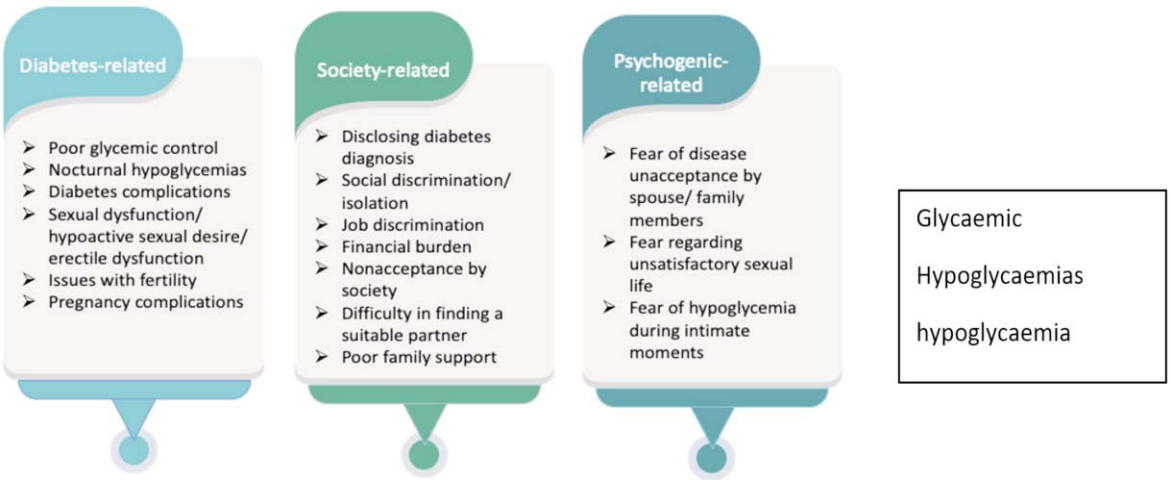


Figure-8: Marital challenges faced by individuals with type 1 diabetes[87]

type 1 diabetes in India face numerous social and psychological marital challenges. They also highlighted that Indian society was not diabetes-friendly (Figure 8).[87]

Misconception regarding social, occupational, marital abilities, fertility, genetics, quality of life, and sexism in young people living with T1DM raises major barriers to marriage. They are often considered sick and disabled with reduced life expectancy, thus unsuitable for marriage. Contrary to societal belief, the risks of having a child with type 1 diabetes are higher if the father is affected than if the mother has type 1 diabetes. However, the absolute risk is minuscule in both cases. A study in central India observed that 85% of unmarried diabetic individuals were unwilling to accept a diabetic groom or bride. Diabetic distress was a major marital issue in young people with diabetes.[88]

2.7.6 Diabetes distress and gestational diabetes

Pregnancy is a phase of important physiological and psychological adaptations. Diabetes and distress are common components of gestational health problems. The stress-enhancing effect of hyperglycaemia and insulin induces the psychological burden of chronic disease in pregnancy.[89]

A prospective cohort study of 100 women diagnosed with gestational diabetes reported elevated diabetes distress scores (PAID score ≥ 8) in 36% of the women. Multivariate analyses demonstrated a strong association between high scores of diabetes distress and adverse pregnancy outcomes (p=0.02).[90] Another comparative descriptive study observed significantly higher scores on the Perinatal Distress scale and Edinburgh Postpartum Depression scale in 153 women with gestational diabetes than in healthy women. Prenatal distress was associated with higher levels of depressive symptoms.[90] A pilot, prospective, observational study conducted for 4 months in 31 women with pregestational, and gestational diabetes identified 58% of women with severe DD symptoms, while 38% had scores in the range of severe DD. Higher scores of DD correlated with high emotional burden and diabetes regime-related concerns. The authors concluded that pregnant women are susceptible to diabetes-specific distress irrespective of demography or clinical differences.[91]

2.7.7 Diabetes distress and work outcomes

Diabetes can negatively affect work-life, decreasing employment opportunities and limiting work opportunities.[92] People with diabetes often struggle to incorporate diabetes management activities into their work schedules. Workplace time pressure often disrupts their willingness and ability to attend clinical appointments. Lack of routine in the work environment was another factor affecting adequate diabetes management.[93]

An online survey-based study of 297 working adults with type 1 diabetes reported that social diabetes distress reflected a significant negative correlation with job satisfaction.[92]

Diabetes-specific factors and work are related to fatigue in employees with diabetes. Lack of social support at work, high job demands, and the burden of adjusting insulin doses to the circumstances appreciably affect fatigue levels.[94]

A questionnaire-based cross-sectional Indian study reported that almost 60% of the population with diabetes distress had productivity losses in the form of paid or unpaid work. 20.6% of individuals reported moderate to high levels of diabetes distress that warranted clinical attention.[95]

2.7.8 Diabetes distress and dietary modification

Adjusting from a normal eating pattern to a diabetic diet can be stressful for patients. Food stress in the context of inadequate money for food, insufficient time for cooking or buying, inaccessibility to food, and special diets are significantly related to diabetes-specific distress. The absence of diabetic-friendly options in shared meals and lack of nutrition knowledge adversely affect eating habits. Mental health guides food choices, while certain foods help as coping strategies to manage mental health.[96]

A cross-sectional survey-based Bangladeshi study observed diabetes distress in more than one-third of the participants with type 2 diabetes. Participants who had higher dietary diversity were less likely to have DD (p = 0.004).[97]

2.7.8.1 Diabetes distress and Fasting

Fasting during the month of Ramadan has been found to be beneficial both to physical health and mental and social well-being.

Fasting during Ramadan was significantly associated with reduced depression and Diabetes distress in individuals with T2DM.[98] Fasting can be considered as meditation-based relaxation techniques and mindfulness which

might help reduce DD in participant who fasted.

3.0 Management of Diabetes Distress

DD management is non-pharmacological and highly individualized and varies according to patient and caregiver needs, health care provider ability, and health care system policy. To correct the stress situation, one must improve self-perception and coping skills and/or involve other partners to minimize the burden that needs to be coped with. First step of management is early recognition of psychosocial problems during diabetes which may affect their ability to adjust to distress and take responsibility for self-care.

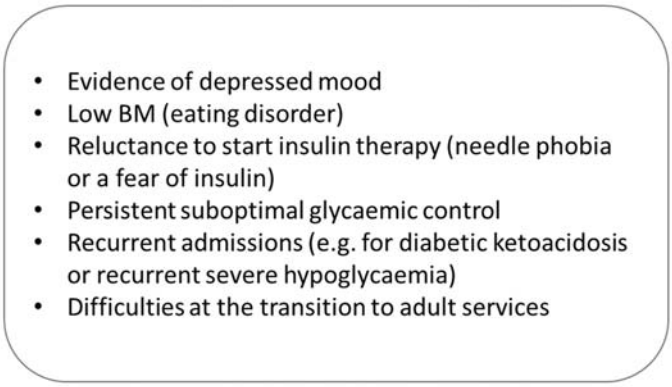


Figure-9: Indication of high-risk comorbid mental health problems in diabetes [99]

- Figure 9 shows the list of red flags to identify high-risk comorbid mental health problems, which can help to identify diabetes distress and treat it early[99]
- Kalra S et al.[26] have suggested four pillars of management of diabetes distress, which are non-pharmacological and based on patient-provider conversation and communication. These 4 pillars include minimising the discomfort associated with changes, strengthening self-care skills, optimisation of coping skills, and utilisation of support from other stakeholders like healthcare professionals, family, and community etc.

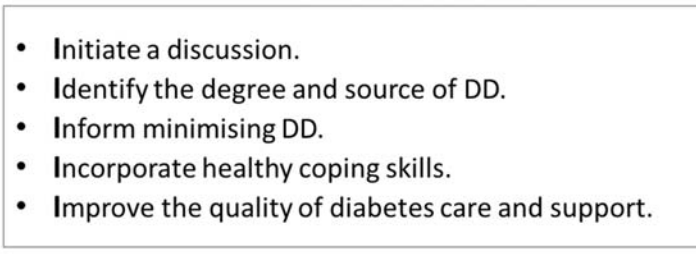


Figure-10: Five "I" Strategy as an approach to DD

- A diabetic person needs to change many aspects of his or her life and is sometimes overwhelmed by the condition. These changes need to be minimised by the step-wise process of informed decision-making and allowing choice by breaking changes into discrete bits, prioritising action, and focusing only on essentials and review of such decisions if needed/indicated (s).[100]
- 5 "I" Strategy as an approach to DD (figure 10): Initiating discussion to identify possible stressors, informing the patient about methods to minimize DD, and helping incorporate positive coping mechanisms to improve outcomes.[26]
- Diabetes distress should be incorporated into comprehensive clinical practice customized to meet the needs of the clinicians and patients. Fisher et al. provided five general strategies to consider when developing structured interventions to reduce diabetes distress.[101] (Figure-11)

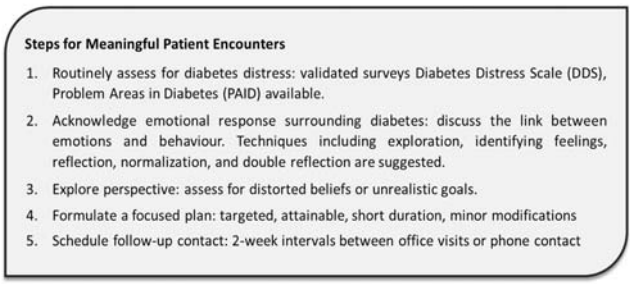


Figure-11: Strategies to consider for reducing diabetes distress.[101]

3.1 Capacity Building:

- Capacity Building integrated a collaborative, multidisciplinary approach for DD prevention and management. This includes creating awareness of the condition and its differential diagnosis, communicating with the patient and offering appropriate interventions effectively, and the foresight to refer to other healthcare professionals when necessary. A "7 A model" responding to DD proposed by ADA, suggests a series of actions to the clinicians while dealing with such patients which include Aware, Ask, Assess, Advise, Assist, Assign and Arrange.[102] Various acronyms have been developed which help physicians to develop patient-centred professionalism. To address DD effectively, diabetes care professionals should have 5 qualities called CARES;[103] C: confident competence; A: accessible authenticity; R: reciprocal respect; E: expressive empathy and S: straightforward simplicity. Using

C: CONFIDENT COMPETENCE	A : ACCESSIBLE AUTHENTICITY	R: RECIPROCAL RESPECT	E : EXPRESSIVE EMPATHY	S: STRAIGHTFORWARD SIMPLICITY
• Scientific competence is a pre-requisite for any counsellor • A positive body language, friendly, resonant voice with pitch modulation, along with non-verbal gestures radiates strength and security from the counsellor to the patient	• Authenticity is a soft skill, which means genuineness, trustfulness, honesty • Diabetics care provider should be able to convey his/her humanness and concern to the patient • The counseller should be easily accessible to patient	• Age-specific and gender-specific body language should be used to convey a sense of professionalism, tempered with caring for the diabetic and convey respect for the patient. • Behaviour should neither be arrogant, nor should it be deferential	• It is a soft skill that implies treating the patient as oneself. • Empathizing means collaboration between equals not enough to develop the soft skill of empathizing or internalizing the patient's problems; one has to convey to the patient that this has been done	• Communication with patient: Whatever is asked, stated or explained should be done in a simple, straightforward and short manner. • The patient should feel relaxed, and should be encouraged to communicate his or her concerns to the counsellor

Figure-12: CARES: Soft skills of Physicians to handle DD.[103]

these skills, health professionals can counsel patients with diabetes effectively. (Figure-12)

- Another tool "WATER" has been suggested that ensures provider-patient bonding, and involvement of patients and improves therapeutic outcomes.[104] The mnemonic WATER (Warm welcome; Ask and assess; Tell the truth; Express empathy; Reassurance and regular follow up) involves a checklist designed for healthcare professionals to change the patient's attitude toward problematic behaviours and improve diabetes care-related behaviours.
- Physicians' empathy plays an integral part of patient-physician relationship both in critical care and general practice. The effective use of empathic communicative skills may be one of the best ways to improve patient satisfaction and patient compliance. A correlational study design using 891 diabetic patients showed that patients of physicians with high empathy scores were significantly more likely to have good control of haemoglobin A1c (56%) than were patients of physicians with low empathy scores (40%, $P < .001$).[105]

3.2 Coping Skills Enhancement

- Coping skill is important for both patient as well as treating physician. It involves skills of cognitions and behaviours mobilized to manage internal and external stressful situations.
- Coping should ease stress, provide comfort, or enhance one's mood in a difficult situation and have a constructive, lasting impact on the mind and body.
- Coping strategies are recommended for patients with difficulty in adjusting to treatment and lifestyle modifications.[106]
- Coping skills training focuses on improving behavioural skills necessary to achieve psychosocial outcomes and better glycaemic control in patients with diabetes. Mnemonic AEIOU suggests the following actions in step-wise order: Assess coping skills, Explain, and eliminate the negative coping strategies, Introduce and Internalize the positive coping skills, Observe the changes regularly, and upgrade the patient's health-related behaviour.[107]
- Group-based counselling programmes in conjunction with psychological counselling, Cognitive behavioural therapy (CBT) and behavioural family systems therapy-diabetes (BFST-D) reduce diabetes-related stress as well as achieve glycaemic control in problematic diabetics.[108]
- The Ways of Coping Questionnaire (WCQ) assess parents' coping strategies with their child's insulin-dependent diabetes (IDDM).[109]
- Positive coping skills and de-learn negative coping mechanisms such as rumination (excessive thinking about the disease), catastrophising (assuming undue negative impact to the disease), self-blame (blaming oneself for the illness) and other-blame (blaming others for one's condition) in their daily life can improve distress.[110]

3.3 Facilitating behaviour of Physicians

- The relationship of patients with the health care

Table-6: Steps to a Meaningful Physicians-Patient Conversation [57]

Step	Conversation
Initiate dialog about distress	Know that we have reviewed your results, is this what you expected?
Identify and address feelings (frequently: humiliation, overwhelmed, sad, fault, irritation)	Describe how you are feeling about diabetes How have you felt about…?
Recap and respond	To make sure I understand…
Normalization	Often patients share that they feel this way… I can see why you feel that way… Other patients I have cared for with diabetes often feel…
Acknowledge resistance and reflect	On one hand you want to get better diabetes control, on the other hand you are frightened to increase the medication dose…
Add new insight	You feel you don't do anything right with your diabetes. While you struggle with one aspect, you do great at taking medication on time, keeping appointments, and monitoring sugar level so there are many things you are successful at…
Planning	How will you respond the next time you want to skip your medicine?

physicians impacts the management of DD. They appreciate when physicians initiate conversations as they can identify and acknowledge how feelings can be tied to the challenges of diabetes management, and knowing they are not alone in the experience can be reassuring[57] Table 6 shows steps to a meaningful physicians-patient conversation.

3.4 Patient-centred care (PCC)

- Physician should fulfill their duty with responsibility, considering the implications of any decision on patients, their family, their society, and healthcare systems. This is possible only if patients are involved in the decision regarding their management. The ten R's of responsible patient-centred care are Respect, Responsiveness, Restrain from self-harm, Realistic approach, Resource husbandry, Relevance, Reaching out, Restrain from other harm, Revision, when needed/anticipated and Reflection[111]. This improves patient satisfaction and compliance.
  - Patient involvement is ensured by improving their knowledge and awareness regarding their disease and treatment options available. It is possible via various means nowadays: Diabetes literacy- and numeracy education tool kit (DLNET) modestly improved self-efficacy and glycaemic control compared with standard enhanced diabetes care [112]
  - "Johari window", a self-awareness tool that aids in better handling of one's emotional and personal issues, which will further boost self-esteem in diabetes patients.[113]
- Importance of training of practice nurses and general practitioners in patient-centred care.
  - Healthcare professionals should receive at least informal and, preferably, formal training in psychological interventions involving coping and counselling for improved patient satisfaction and therapeutic outcomes.
  - Patients in routine care with additional training have reported better communication with the doctors, greater treatment satisfaction and wellbeing.[114]

3.5 Family therapy:

- Involving family members/care givers helps to reduce the impact of stress and mental health disorders associated with diabetes, particularly in children and adolescents, reducing diabetic-related conflict between family members.
- Physicians should implement family-oriented programmes for individuals with diabetes to explore the role of family support.[115]
- Behavioural Family Systems Therapy for Diabetes (BFST-D) is a flexible, multi-component intervention targeting family communication and problem-solving.
  - 10 sessions of BFST-D over 3 months improved family communication and problem-solving as measured by parent and adolescent report.[116]
  - BFST-D significantly improved the quality of family interaction compared to standard care (SC) (10 of 12 comparisons) and educational support group (ES) (6 of 12 comparisons).[117]

3.6 Training of practice nurses and general practitioners in patient-centered care

- Healthcare professionals should receive at least informal and, preferably, formal training in psychological interventions. involving coping and counselling.
- Compared with patients in routine care, patient in routine care plus additional training reported better communication with the doctors, greater treatment satisfaction and well-being.[114] This shows power of consultation process than preventive care among trained clinical practitioners.
- Ability of health professionals to counsel patients with diabetes must be enhanced by receiving training in specific courses associated with teaching and counselling techniques. As mentioned in figure-13, course content should emphasise skills in four major categories.

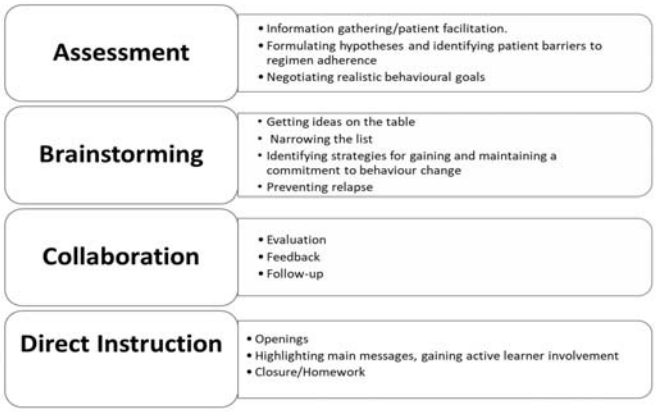


Figure-13: Effective engaging patients in diabetes-related problem solving[118]

3.7 Developing Support groups

One of the most important aspects of developing diabetes awareness is providing support groups to people living with diabetes. The stereotypes surrounding these people can be very hurtful, by increasing awareness we can highlight that a wide range of ages, races and lifestyles can be affected by diabetes. Social media is a great way to reach out to group people who are living with diabetes. On line support groups can go a long way in increasing awareness and reducing psychological burden associated with it.

3.8 Quality improvement initiatives for type 1 diabetics in health care system

Quality improvement initiatives are systematic and continuous actions that lead to measurable outcomes in healthcare services and health status of targeted patient population.

4.0 SAFES Recommendation and Action Plan

4.1 Methodology

The current recommendation has been developed following the AACE protocol. (Table A) Recommendations are assigned evidence level (EL) ratings based on the quality of supporting evidence, all of which have also been rated for strength (Table B).

The South Asian Federation of Endocrine Societies (SAFES) is an association of seven national professional bodies in South Asia: Afghanistan Endocrine Society, Bangladesh Endocrine Society, Diabetes and Endocrinology Association of Nepal (DEAN), Endocrine Society of India, Endocrine Society of Maldives, Pakistan Endocrine Society and Sri Lanka College of Endocrinologists.

Table-A: Evidence rating according to the 2010 American association of clinical endocrinologist protocol [119]

Evidence level	Reference methodology
1	Meta-analysis of randomised controlled trials (MRCT) Randomised controlled trials (RCT)
2	Meta-analysis of nonrandomised prospective or case-controlled trials (MNRCT) Nonrandomised controlled trial (NRCT) Prospective cohort study (PCS) A retrospective case-control study (RCCS)
3	Cross-sectional study (CSS) Surveillance study (registries, surveys, epidemiologic study, retrospective chart review, mathematical modelling of database) (SS) Consecutive case series (CCS) Single case reports (SCR)
4	No evidence (theory, opinion, consensus, review, or preclinical study) (NE)

1 = strong evidence; 2 = intermediate evidence; 3 = weak evidence; and 4 = no evidence.

Table-B: Recommendation grading according to the 2010 American association of clinical endocrinologists' protocol [119]

Grade	Strength of recommendation
A	Strong
B	Intermediate
C	Weak
D	No evidence-based

The first draft of the recommendations was prepared before the meeting after a thorough literature search about each class of recommendations pertinent to the SAFES countries. This was circulated amongst the experts for their detailed review before the meeting. The experts discussed the draft and provided suggestions, comments, and modifications. A revised draft based on the discussions during the meeting was prepared and circulated among the experts via e-mail for the final recommendations. Post-approval from all the attending experts, the finalised draft was submitted for publication.

4.2 Recommendation-1: Defining Diabetes Distress:

- DD is a psychological state which is a unique, often hidden, emotional burden and worry that a patient experiences when he/she is managing a severe chronic disease such as diabetes. This is found in persons with diabetes and their caregiver. (Grade A; EL 2).
- DD has been defined across domains relating to (1)

Diabetic regimen, i.e., the monitoring of blood glucose, dietary control, and increasing physical activity; interpersonal or relational issues, referring to conflicts with carers, partners, and friends; and (2) Emotional burden, i.e., feeling demotivated, unsupported emotionally, misunderstood and worrying about future complications. (Grade A; EL 2)

- Recent evidence defines DD as an Emotional response characterized by extreme apprehension, discomfort, or dejection, due to a perceived inability to cope with the challenges and demands of living with diabetes (Grade A; EL 2).
- Diabetes distress and depression can exist separately or co-occur but need separate treatment (Grade A; EL 2).

4.3 Recommendation-2: Epidemiology:

- Worldwide, DD may affect as many as 40% of people diagnosed with diabetes.
- A cross-sectional descriptive study in a noncommunicable disease clinic of a tertiary care medical centre in India reported 42% DD in nondepressed type 2 diabetes mellitus. Bangladesh showed a high prevalence of DD in patients with T2DM. 52.5% had DD, 29.7% had moderate, and 22.8% had high DD.
- Need more prevalence data from other SAFES member countries through their surveys. (Grade A; EL 4).

4.4 Recommendation-3: Risk factors:

- Different factors related to patients, Family and friends and Caregivers or physicians should be considered as contributions to DD (Grade A; EL 2).
- seven major sources of diabetes distress identified as Powerlessness, Negative Social Perceptions, Physician Distress, Friend/Family Distress, Hypoglycaemia Distress, Management Distress, and Eating Distress (Grade A; EL 2).
- Precipitating factors of diabetes distress include changes in life, disease state, health care, and disease management (Grade A; EL 2).

  increased over the past 22 years.

4.5 Recommendation-4: Symptoms:

- The symptoms of DD are like those of depression but are not severe enough to qualify as major depressive disorder (MDD). (Grade A; EL 3).
- Core symptoms of DD are listed in figure 4.

4.6 Recommendation-5: Detection:

- DD should be detected using validated screening and diagnostic tools, as mentioned in Table 5 (Grade A; EL 2).
- Training of general practitioners and physicians in the identification and management of psychiatric comorbidities in rural and urban areas is recommended (Grade B; EL 2).
- From the Indian perspective, consider the Self-perception of Health Questionnaire, WHO-5, PAID and other diabetes specific questionnaires available in local languages as suitable tools (Grade B; EL 2).
- When DD is identified, healthcare professionals should explain the link between these and poorer diabetes control.
- Assessment of the patient's psychological and social situation must be part of the diabetes management using reliable, validated tools.
- DDS provides a quantitative assessment of the degree of DD. DDS is not designed to identify specific shortcomings or weaknesses in coping styles that can be targeted to improve the emotional health of patients with DD. The assessment of coping skills is, therefore, suggested as a primary investigation for DD treatment as well as prevention.
- The GlucoCoper – a Tool for the Assessment of Coping Mechanisms is recommended (Grade A; EL 3) This can be used as a brief and effective screening tool for dysfunctional coping skills in pregnancy complicated by diabetes. (Grade B; EL 2).

4.7 Recommendation-6: Diabetes Fatigue:

- Fatigue is commonly encountered in diabetes care, yet it is often neglected. fatigue and diabetes lead to a bidirectional relationship, creating the vicious cycle of DFS. So, needs to be measured.
- Non-endocrine factors such as an unhealthy and sedentary lifestyle, poor sleep hygiene, and drug abuse should be identified through careful history taking. (Grade B; EL 4).
- Endocrine factors leading to DFS must be assessed through a targetted gluco-endocrine evaluation. (Grade B; EL 3).
- The ABCDE approach can aid in ruling out the psychosocial and biomedical causative factors of DFS (psychosocial/biomedical-Apnoea/Anaemia, Behavioural issues/Bulimia, Conditioning/Comorbid conditions, Drug-induced/Diabetes complications, Exercise/Endocrine dysfunction). (Grade B; EL 4).
- The severity of diabetes and sleep quality are strong predictors of diabetes fatigue. (Grade B; EL 3).
- A systematic and strategic diagnostic plan must be followed based on the glycaemic status, biochemical and psychological aspects, lifestyle and diet-related

factors, and diabetic complications.

4.8 Recommendation-7 Diabetes distress in special conditions:

- As children with diabetes transition to adolescents, their diabetes distress becomes psychologically difficult to control. Adolescent girls tend to have greater difficulty in coping with DD. Thus, age- and gender-specific treatment regimens must be offered to minimise the burden of living with diabetes. (Grade B; EL 3).
- Most young adults experience a limiting influence of diabetes, due to which they struggle to balance their diabetes and daily activities.
- Diabetic distress is a major marital issue in young people with diabetes owing to misconceptions regarding fertility, genetics, and sexism.
- Women with gestational diabetes should be evaluated for distress levels as it can have adverse pregnancy outcomes. (Grade A; EL 3).
- Workplace time pressure and lack of routine can induce fatigue in employees with diabetes that may, at times, require clinical attention. (Grade C; EL 3).
- The elderly presents the unique emotional burden of living with diabetes and are more prone to complications. To improve outcomes, this population should be counselled and educated regarding diabetes-specific distress experiences. (Grade B; EL 3).
- Food stress has a significant association with diabetes distress. Addressing accessibility to diabetes-friendly diets and improving the community food environment induces diabetes empowerment. (Grade B; EL 3).

4.9 Recommendation-8: Management

4.9.1 Improving awareness/skills of healthcare professionals

4.9.1.1

Formal training in psychological interventions involving coping and counselling for improved patient satisfaction to improve distress. (Grade A; EL 1).

4.9.1.2

Psychological reactions and coping mechanisms operate at the time of diagnosis of diabetes and continue all through management. (Grade A; EL 3).

4.9.1.3

Training in specific courses associated with teaching and counselling techniques, such as "Effective Patient Teaching and Problem Solving, SWOT analysis and CARES (Grade A; EL 3).

4.9.1.4

"Water Approach to involve patients actively, ensure provider-patient bonding and improve therapeutic outcomes. (Grade A; EL 4).

4.9.2 Improving awareness among patients

4.9.2.1

Diabetes education using interactive modules such as diabetes literacy and numeracy education toolkit. (Grade A; EL 1).

4.9.2.2

Self-awareness tools such as "Johari Window" in patients with diabetes to enhance his/her knowledge about themselves that aid in better handling of one's emotional and personal issues, which will further boost their self-esteem (Grade A; EL 4).

4.9.2.3

Creation of India specific interactive tool where most patients present with low health literacy/numeracy (Grade A; EL 4).

4.9.3 Preventive measure

4.9.3.1

Behavioural Family Systems Therapy for Diabetes (BFST-D) in combination with educational support is recommended for the improvement of family communication and problem-solving (Grade A; EL 1).

4.9.3.2

Family therapy should be recommended in children to allow for a better balance between parental and self care of the child (Grade A; EL 3).

4.9.3.3

Explore the role of family support and family functioning in implementing family-oriented programmes for individuals with diabetes (Grade A; EL 4).

4.9.4 Management Therapies

4.9.4.1

Cognitive behavioural therapy (CBT) should be recommended either alone or in combination with other strategies to diabetes patients with co-morbid DD (Grade A; EL 1).

4.9.4.2

Long-term motivational therapy with suitable follow-up is recommended in combination with CBT for improvement in HbA1c levels (Grade B; EL 1).

4.9.4.3

Therapy should be individualized and is recommended in children/adolescents for improvement in behaviours and adherence and adults for dietary behaviour (Grade A; EL 1).

4.9.4.4

Group-based counselling programmes in conjunction with psychological counselling, CBT, and behavioural family systems therapy-diabetes (BFST-D) (Grade A; EL 1).

4.9.4.5

BFST-D, in combination with education, helps in reining problem solving skills for reducing family conflict and improving treatment adherence to achieve better glycaemic control (Grade A; EL 1).

4.9.4.6

Greater social support, patient empowerment and supporting coping skills must be considered among women with diabetes (Grade A; EL 2).

4.9.4.7

Family physicians should encourage patients with diabetes to integrate positive coping skills and de-learn negative coping mechanisms (Grade A; EL 2).

4.9.4.8

Therapy to improve resilience resources and coping strategies of patients is recommended in patients finding difficulty in adjustment with treatment and lifestyle modification (Grade B; EL 3).

4.9.4.9

Therapies such as problem-solving and MI should be individualised in children/ adolescents with diabetes for enhancement in behaviours, adherence to medication and change in dietary patterns for improved glycaemic control (Grade A; EL 1).

4.9.4.10

In adolescents, Problem focused coping strategies and behavioural coping skills are recommended (Grade A; EL 3).

4.9.5 Educational Programme

4.9.5.1

Group education programmes, including coping skills, behavioural-cognitive skills, relaxation techniques, problem-solving skills, mindfulness-based stress management and family therapy, are to be considered (Grade B; EL 3).

4.9.5.2

In patients with low health literacy and numeracy, diabetes education may be facilitated using interactive modules.

4.9.5.3

Therapeutic patient education through a patient-centred approach.

4.9.5.4

Healthcare professionals should receive formal training in CBT (Grade A; EL 1).

4.9.5.5

Physicians should receive formal training in interventions involving MI, like WATER.

4.9.5.6

Problem-based approach in conjunction with diabetes self-management education, patient empowerment and life-long management programmes to improve diabetes-related outcomes and quality of life.

4.9.6 Custom/religion

4.9.6.1

Indian physicians, should be sensitised to the importance of cultural and religious health attributes, beliefs, and practices (Grade A; EL 4).

4.9.6.2

Standardized screening questions to enquire about the role of religion and spirituality in the patient's life (Grade C; EL 4).

4.9.6.3

Recommend pilgrims to educate them about Hypoglycaemia and other DD (Grade A; EL 3).

4.9.6.4

Education about the importance of a balanced diet, moderate physical exercise, adherence to advised medications, self-monitoring of glycaemia, early recognition of dangerous situations and necessary remedial measures (Grade B; EL 4).

4.9.6.5

Religious and cultural leaders should be encouraged to speak positively about modern diabetes care (Grade A; EL 4).

Conclusion

Diabetic distress is an unfortunate but probable aspect of living with diabetes. An extensive comprehension of the causes, clinical characteristics, and diagnostic evaluations of this condition can enable diabetes healthcare providers

to interact with individuals affected by it and their caregivers with sensitivity and empathy. This SAFES recommendation intended to inspire all stakeholders involved in diabetes care to dedicate sufficient time and resources towards ensuring the best possible management of diabetes distress. Addressing diabetes distress can have a positive impact on the emotional well-being of individuals with diabetes and their ability to manage their condition effectively. It is essential to prioritize the identification and treatment of diabetes distress in order to provide comprehensive care for individuals with diabetes.

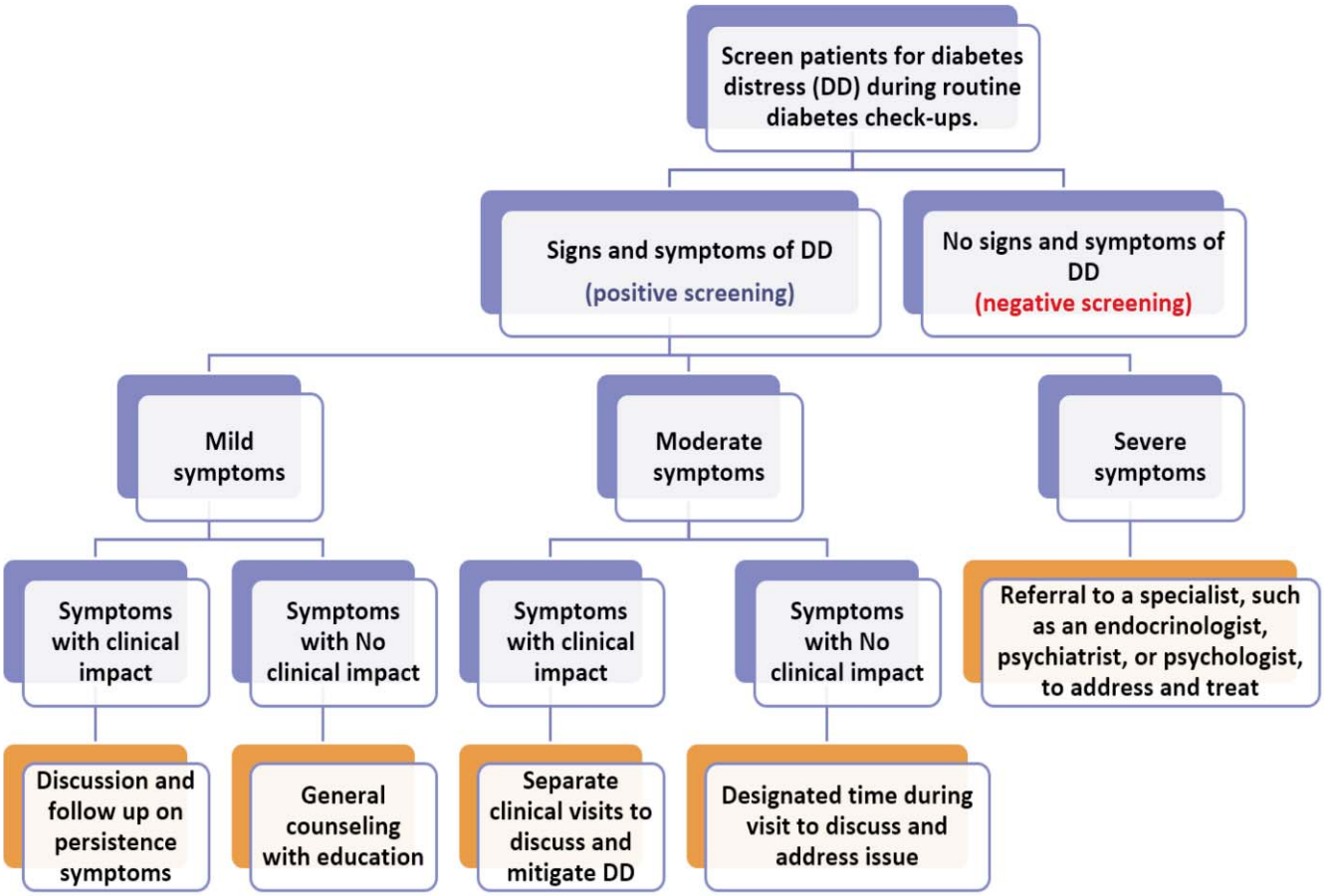
A. Summary of recommendations

1. Evidence for the summary

1. DD affects a significant proportion of people diagnosed with diabetes worldwide.
2. DD risk factors include patient-related, family-related, and physician/caregiver-related factors.
3. The seven major sources of DD include powerlessness, negative social perceptions, physician and friend/family distress, Hypoglycaemia distress, management distress, and eating distress.
4. The symptoms of DD resemble those of depression, but they are not intense enough to meet the criteria for a diagnosis of major depressive disorder.
5. Fatigue in diabetes is often neglected. It leads to a bidirectional relationship creating a vicious cycle of diabetes fatigue syndrome (DFS).
6. Age, gender, and life stage influence the psychological burden of living with diabetes, necessitating age and gender-specific treatment regimens.
7. Fatigue induced by workplace time pressure may require clinical attention. Addressing accessibility to diabetes-friendly diets and improving the community food environment can alleviate food stress and induce diabetes empowerment.

2. Key recommendations

1. Improving the awareness and skills of healthcare professionals is essential for addressing diabetes distress.
2. Detecting and managing diabetes distress (DD) is important in diabetes management. Validated screening tools, such as the Self-perception of Health Questionnaire, WHO-5, and PAID, can be used for assessment.
3. The ABCDE approach can aid in ruling out psychosocial and biomedical causative factors, and a systematic diagnostic plan should be followed based on glycaemic status, lifestyle, and diabetic complications.
4. Formal training in psychological interventions involving coping and counselling can improve patient satisfaction. Healthcare professionals should receive training in specific courses associated with teaching and counselling techniques, and the Water Approach can be used to involve patients actively and improve therapeutic outcomes.
5. To improve patient awareness, healthcare providers can utilise interactive diabetes education modules and self-awareness tools such as the "Johari Window".
6. Additionally, Interactive tools can be created to cater to patients with low health literacy/numeracy. These measures can aid patients in better handling their emotional and personal issues, enhancing their knowledge about themselves, and boosting their self-esteem.
7. Preventive measures for diabetes distress include utilising Behavioural Family Systems Therapy (BFST-D) and educational support to improve family communication and problem-solving.
8. Managing diabetes-related psychological distress can involve customised therapies such as cognitive-behavioural therapy (CBT), motivational therapy, and family therapy, with or without group-based counselling programmes.
9. BFST-D combined with education can improve problem-solving skills, reduce family conflict, and enhance treatment adherence for better glycaemic control. Patients with difficulty adjusting to treatment and lifestyle modifications may benefit from therapy to improve resilience resources and coping strategies.
10. Coping skills, problem-solving, and motivational interviewing can be individualised to enhance adherence and dietary patterns for better glycaemic control in children and adolescents.
11. Health professionals should explain the link between DD and diabetes control and assess the patient's psychological and social situation. The GlucoCoper tool is recommended for screening and addressing dysfunctional coping skills in pregnancy complicated by diabetes.
12. Group education programmes incorporating coping and cognitive-behavioural skills, relaxation techniques, problem-solving skills, mindfulness-based stress management, and family therapy are recommended.
13. For patients with low health literacy, interactive modules may be used for diabetes education, and healthcare professionals should be trained in CBT



Flow chart for patient screening and treatment.

and MI interventions.

14. Problem-based approaches, diabetes self-management education, patient empowerment, and lifelong management programmes can improve diabetes-related outcomes and quality of life.
15. To improve diabetes management among patients from different cultural and religious backgrounds, Physicians should be sensitised to cultural and religious beliefs and practices.
16. Standardised screening questions may be used to enquire about the role of religion and spirituality in the patient's life.
17. Educating pilgrims about hypoglycaemia and other diabetes-related complications is recommended—a recommendation for religious and cultural leaders to speak positively about modern diabetes care.

B. The 3-screening tool recommended by SAFES.

1. DDS-17
2. PAID-5
3. Type-1 DDS

C. Flow chart for patient screening and treatment

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